

**The challenge of cross-cultural comparability in survey  
research: a case study of the Rose Angina Questionnaire**

**Lisa Hanna**

Thesis presented for the degree of Doctor of Philosophy  
University of Edinburgh  
2004



## **Declaration**

I hereby declare,

- (i) That this thesis has been composed by myself
- (ii) That the work presented within this thesis is my own unless otherwise stated
- (iii) That this work has not been submitted for any other degree or professional qualification

Lisa Hanna

2004



## Acknowledgements

I am immensely indebted to a large number of people for their assistance throughout this project. I would particularly like to thank the following:

My supervisors Professor Raj Bhopal and Dr. Sonja Hunt for their time, guidance and encouragement.

The bilingual project workers employed on this study: Maqsood Ahmed, Munazzah Aslam, Carmen Chan, Jeanice Lee and Jan Khalid, for their dedication in recruiting participants, carrying out and translating interviews, and providing cultural commentary.

All of the research participants who so generously gave their time to the project.

My colleagues Dr. Sushmita Wiebe and Dr. Colin Fischbacher for their assistance, advice and support.

Professor Harry Keen for his correspondence regarding the Rose Angina Questionnaire.

Alastair Christie at the Edinburgh and Lothians Racial Equality Council, who gave advice on the project and provided me with contacts to the relevant ethnic minority community organisations.

Mohammed Hameed at the City of Edinburgh Council's Equalities Unit, who gave advice on the project.

The community representatives and groups I visited in Edinburgh, who helped with advice, project worker and participant recruitment for the study: Masud Khan at Alpha Interpreting and Translating Services; Nagras Masood and Farhat Raza at the APNA Pakistani Women's Group; Shami Khan and colleagues at the Pakistan Society; Ben Yuen and Kathy Millar at the Edinburgh Chinese Elderly Support Centre; and Sophie Pilgrim at the Minority Ethnic Learning Disabilities Initiative.

The staff at various organisations in Edinburgh- Skillnet, Saheliya, Men in Mind, MILAN Senior Welfare Council, Nari Kallyan Shangho and Women onto Work- who also circulated advertisements for bilingual project worker posts.

The staff at Lothian Primary Care NHS Trust's Minority Ethnic Inclusion Project, who gave assistance and advice on participant recruitment and interviewing, and circulated advertisements for bilingual project worker posts:

Sumita Grant, Anita Bhatnagar, Jenny Chan, Sau-Mei Fong, Fulmaya Lama, and Sana Sadollah.

Antonia Ineson at Lothian Health who was the independent adviser for the study, available to respond to concerns or queries about the project from research participants.

Integrated Language Services at Heriot-Watt University, for translations of participant information sheets, letters and consent forms.

Jenny Chan and Attika Sultana for proofreading the Chinese and Urdu translations of the above study materials.

The staff at 3 General Practices involved with this study, particularly the practice managers Linda Blackmore, Carrie Anderson and Margaret Barrowman who facilitated identification of study participants and co-ordinated the return of consent forms; and the doctors Dr. Alec Millar, Dr. Rosie Dixon, Dr Claire Macdonald, Dr. Mike Brough and Dr. Susan Nickerson who screened lists of potential participants and signed letters to participants.

Dr. Judith Bush from the University of Newcastle, and her colleagues, for their guidance on selecting and training bilingual ethnic minority community members to carry out qualitative research.

Haidar Mahmoud, Flick Thorpe and other staff at Edinburgh's Community-based English as a Second Language Project for undertaking and facilitating language tests.

Louise Hayes and the Newcastle Heart Project team for supplying the Punjabi and Chinese versions of the Rose Angina Questionnaire used in their study.

Naina Minhas from Nari Kallyan Shangho for making an oral recording of the questions on the Punjabi version of the Rose Angina Questionnaire.

Hazel King for transcribing some English-speaking interviews and for moral support.

Colleagues at Public Health Sciences, University of Edinburgh, for providing a supportive and pleasant working environment.

All my friends and family who have encouraged me throughout the challenging Ph.D. process.

This project was funded by the University of Edinburgh Faculty of Medicine and by a Chief Scientist Office small grant.

## **Abstract**

### **Introduction**

The Rose Angina Questionnaire (RAQ) is an important measure of coronary heart disease prevalence. It has been shown to perform inconsistently across some ethnic groups in Britain. For multi-ethnic survey research, an angina screening instrument with greater cross-cultural validity is required.

### **Objectives**

To assess the need for, and feasibility of, modifying the RAQ to produce a cross-culturally valid angina screening tool for use in Punjabi, Cantonese and English speakers.

### **Methods**

Key principles of cross-cultural adaptation were extracted from the literature. Cardiovascular research was reviewed and it was established that no adequate prior work on the cross-cultural comparability of this questionnaire had been carried out. Interviews were carried out with samples from the three main language/cultural groups in Scotland: Pakistani Punjabi speakers (n=26), Chinese Cantonese speakers (n=29) and European-origin English speakers (n=25) living in Edinburgh. Bilingual project workers were employed to interview participants in their own language and provide translation and commentary to the English-speaking researcher. Samples were obtained from General Practitioner lists, community groups, and project workers' own community contacts. Participants were encouraged to speak about their general and cardiovascular health beliefs and related behaviours, and about their experience of and attitudes to pain and chest pain. They were also asked to comment on the appropriateness of the wording and response options used in Punjabi, Cantonese and English versions of the RAQ as developed by the Newcastle Heart Project.

## **Results**

Participants expressed a range of health beliefs and behaviours. Perceptions and significance of pain and chest pain varied. However, whilst there were some themes that varied between groups, no dominant themes in the cultural construction of health, pain or cardiovascular knowledge emerged that may significantly influence RAQ response between language groups. Individual differences such as general anxiety about health, or awareness of cardiac symptoms, were more likely to affect perception of, and response to, RAQ items. Problems were encountered with the Punjabi and Cantonese translations of the RAQ, where inappropriate translations may have produced distorted data on angina prevalence. For example, the translation for "chest" was interpreted by some Pakistani and fewer Chinese women to mean "breasts". "Walking uphill" was translated in Chinese as "walking the hill", without stipulation of the direction, so that some Cantonese speakers interpreted the question as pertaining to walking downhill. In addition, many Chinese interpreted RAQ items to be referring to breathlessness rather than chest pain due to ambiguous wording. Standardised administration of questionnaire items by an interviewer may also be difficult to establish. First, the process may be much more discursive in practice than epidemiological rigour would demand. Second, as Cantonese is an oral language, the written Chinese script must be spot-translated by the Cantonese-speaking interviewer. The process of lay assessment of questionnaire appropriateness using bilingual project workers also raised methodological challenges- the assessment task was difficult for participants to understand and for bilingual project workers to implement. Quality control of data generated by bilingual project workers in languages not spoken by the researcher was problematic.

## **Conclusion**

There is evidence that existing Punjabi and Cantonese versions of the Rose Angina Questionnaire should be modified further before being used in multi-ethnic surveys. Current versions are unlikely to be yielding data that is equivalent or comparable across groups. Other language versions may also require investigation to ensure

comparability. Recommended methodology, which involves lay participants in questionnaire assessment, is time and resource intensive and can be challenging.

# Contents

Chapter	Page
<b>1 Introduction .....</b>	<b>1</b>
<b>2 Ethnicity, coronary heart disease, and angina measurement in epidemiological studies.....</b>	<b>8</b>
2.1 A multiethnic Britain.....	9
2.2 Ethnic variations in coronary heart disease .....	11
2.3 Angina measurement in multi-ethnic surveys .....	14
2.4 The Rose Angina Questionnaire: development and versions.....	16
2.5 General research with the Rose Angina Questionnaire.....	19
2.6 Use of the Rose Angina Questionnaire in different ethnic groups .....	23
2.7 Cross-cultural adaptation of the Rose Angina Questionnaire.....	29
<b>3 Cross-cultural health survey research and the Rose Angina Questionnaire .....</b>	<b>35</b>
3.1 Chapter overview .....	36
3.2 Ethnicity, culture and language as variables in epidemiological research .....	36
3.3 Study methodology: a theoretical context .....	40
3.4 Cross-cultural adaptation of questionnaires	
3.4.1 Background .....	43
3.4.2 Problems with cross-cultural adaptation methodology.....	45
3.4.3 Principles of cross-cultural adaptation methodology.....	48
3.4.4 Methodological implications for the cross-cultural adaptation of the Rose Angina Questionnaire.....	54
3.5 Cross-cultural health survey research and relevance to the Rose Angina Questionnaire.....	55
3.6 Symptom perception and self-report: cultural differences in symptom perception and relevance to the cross-cultural validity of the RAQ.....	56
3.7 Possible factors affecting symptom perception, self-report and RAQ response.....	58
3.7.1 Pain.....	59
3.7.2 Knowledge of heart disease and symptoms of	

	angina and heart attack .....	60
3.7.3	Beliefs about chest pain .....	61
3.7.4	Somatisation/somatic awareness and concerns about health .....	62
3.7.5	General health experience .....	63
3.7.6	Consultation behaviour and attitudes to health care .....	64
3.7.7	Information about health .....	65
3.7.8	Exercise .....	65
3.8	Conclusion concerning cross-cultural adaptation of the RAQ .....	66
<b>4</b>	<b>Aims and Methods .....</b>	<b>67</b>
4.1	Background to aims .....	68
4.2	A note on development of aims .....	68
4.3	Aims .....	70
4.4	Development of study design and materials .....	71
4.5	Preliminary community consultation .....	77
4.6	Participant Recruitment I: initial GP-based sampling strategy .....	77
4.7	Bilingual project workers .....	80
4.8	Low response rates .....	87
4.9	Participant Recruitment II: community based and snowball sampling strategy .....	88
4.10	Characteristics of the sample .....	89
4.11	Interviews: location and content .....	91
4.12	Data preparation, coding and analysis .....	95
4.13	Timeline of study and ethical approval .....	100
<b>5</b>	<b>Cultural appropriateness of the concepts underlying the Rose Angina Questionnaire .....</b>	<b>102</b>
5.1	Introduction .....	103
5.2	Results: General health issues .....	104
5.2.1	Self-reported health and health experience .....	104
5.2.2	Influences on health .....	107
5.2.3	Concerns about health .....	114
5.2.4	Sources of information about health .....	118
5.2.5	Summary of general health issues .....	124
5.3	Results: Angina and coronary heart disease (CHD) .....	124
5.3.1	Understanding of angina .....	124
5.3.2	Symptoms of angina .....	126
5.3.3	Cause of angina .....	129



5.3.4	Source of information about angina .....	131
5.3.5	Understanding of heart disease .....	132
5.3.6	Symptoms of heart disease .....	134
5.3.7	Causes of heart disease .....	136
5.3.8	Summary of knowledge of angina and CHD .....	141
5.4	Results: Expression of, and attitudes to, pain .....	141
5.4.1	Categorising and describing pain .....	142
5.4.2	Pain tolerance .....	147
5.4.3	Pain management .....	148
5.4.4	Summary of expression of, and attitudes to, pain .....	149
5.5	Chapter summary .....	150
<b>6</b>	<b>Investigating whether the Punjabi, Cantonese and English versions of the RAQ are equivalent in each of the study groups .....</b>	<b>151</b>
6.1	Introduction .....	152
6.2	Results: Understanding of RAQ items .....	152
6.2.1	RAQ1a .....	153
6.2.2	RAQ 1b .....	166
6.2.3	RAQ 1c .....	168
6.2.4	RAQ 1d .....	173
6.2.5	RAQ 1e .....	177
6.2.6	RAQ 1f .....	180
6.2.7	RAQ 1g .....	182
6.2.8	RAQ 1h .....	183
6.2.9	RAQ 1i .....	184
6.2.10	RAQ 1j .....	186
6.2.11	RAQ 2a .....	187
6.2.12	RAQ 2b .....	193
6.3	Chapter summary .....	193
<b>7</b>	<b>Factors relating to questionnaire response tendencies .....</b>	<b>195</b>
7.1	Introduction .....	196
7.2	Experiences of, and attitudes to, questionnaires .....	196
7.3	Experience of, and attitudes to, health care .....	202
7.4	Attitudes to taking part in research .....	212
7.5	Chapter summary .....	216
<b>8</b>	<b>Discussion .....</b>	<b>218</b>
8.1	Introduction .....	219



8.2	Discussion of methods .....	221
8.2.1	Inherent strengths and weaknesses.....	221
8.2.2	Methodological challenges and insights.....	230
8.2.2.1	Sampling .....	231
8.2.2.2	Ethical issues .....	233
8.2.2.3	Issues arising through work with bilingual co-workers .....	236
8.2.2.4	Lay assessment of the RAQ .....	247
8.3	Cultural appropriateness of concepts underpinning the RAQ .....	253
8.3.1	General health beliefs and behaviour.....	255
8.3.2	Awareness of chest pain, angina and CHD.....	261
8.3.3	Pain.....	264
8.4	Problems with existing RAQ versions .....	269
8.4.1	Variation in meaning of specific words due to inappropriate translation .....	271
8.4.2	Variation in understanding of terms and question intent between and within groups .....	274
8.4.3	Variations in the wording of items and the form of the questionnaire across languages.....	278
8.4.4	No written form of verbal Cantonese .....	281
8.5	Factors influencing questionnaire response tendencies .....	281
8.5.1	Attitudes to/ experience of questionnaires .....	282
8.5.2	Attitudes to taking part in research.....	283
8.5.3	Health-care seeking behaviour and attitudes.....	284
8.6	Suggestions for postdoctoral research based on this case study.....	286
8.7	Conclusion and recommendations.....	291
<b>References.....</b>		<b>295</b>
<b>Appendices.....</b>		<b>314</b>

## Appendices

Appendix	Page
A1 Publication screening pro-forma for Rose Angina Questionnaire review .....	314
A2 Versions of the Rose Angina Questionnaire used in the Newcastle Heart Project (Punjabi, Cantonese, English) .....	317
A3 Telephone screening interview form .....	323
A4 Communications with Lothian Research Ethics Committee following submission of an application for ethical approval for the study .....	328
A5 Participant contact pack materials in Urdu, Cantonese and English .....	372
A6 Response rates in national and local studies examining tobacco and alcohol use in a range of ethnic groups .....	388
A7 Study proposal submitted to the Chief Scientist Office for additional funding; referees' comments and the researchers' response .....	390
A8 Advertisements for bilingual project worker posts .....	405
A9 Language test administered to applicants for the post of bilingual project worker .....	408
A10 Training pack for bilingual project workers .....	412
A11 Oath of confidentiality for bilingual project workers .....	444
A12 Pre-interview details form .....	446
A13 Interview consent forms in Urdu, Cantonese and English .....	448
A14 Interview field notes form .....	452
A15 Form for recording translated data from non-English interviews .....	454
A16 Timeline for key stages of project preparation and field work .....	459

## **List of Boxes**

Box 3.1	Main spoken/ best understood language from age 50-74 in Indian, Pakistani, Bangladeshi Chinese men and women living in England
Box 3.2	Recommended minimal and optimal principles of questionnaire adaptation
Box 4.1	Interview topic guide
Box 4.2	Timeline for gaining ethical approval for the study

## **List of Tables**

Table 2.1	2001 census data showing ethnic composition of Great Britain and regions
Table 2.2	Angina prevalence and standardised risk ratio in ethnic groups in England
Table 2.3	The Rose Angina Questionnaire
Table 2.4	Performance of Rose Angina Questionnaire in European and South Asian men and women
Table 2.5	Best practice in cross-cultural adaptation of the Rose Angina Questionnaire to date
Table 4.1	Response to advertisement for Punjabi/ English and Cantonese/ English bilingual project workers
Table 4.2	Person Specification/Selection Criteria for the post of project workers for a qualitative study of pain and ill-health in Punjabi and Cantonese men and women
Table 4.3	GP-based sampling responses in 3 linguistic/ethnic groups in Edinburgh
Table 4.4	Characteristics of female participants interviewed
Table 4.5	Characteristics of male participants interviewed
Table 4.6	Numbers of participants interviewed from each source of recruitment

## **List of abbreviations**

CHD	Coronary heart disease
CVD	Cardiovascular disease
RAQ	Rose Angina Questionnaire
NHP	Newcastle Heart Project
MI	Myocardial infarction
ECG	Electrocardiogram
HSE	Health Survey for England
BMEG	Black and Minority Ethnic Groups Health and Lifestyle Survey
GP	General practice, general practitioner
DPSI	Diploma in Public Service Interpreting
NHS	National Health Service

## **Chapter 1**

## **Introduction**

The United Kingdom is evolving into a multiethnic state. This multiculturalism poses challenges to public health researchers and necessitates awareness of, and responsiveness to, the methodological issues involved in carrying out research with different ethnic groups. In order for research to be equitable and culturally salient, it is vital that ethnic minority populations are appropriately represented and that the methods used are culturally sensitive. In addition, public health initiatives and policy directed at the health of ethnic minorities must be based on high quality data.

Survey research is one of the most important methods in public health. A survey has been defined as a non-experimental investigation in which information is systematically collected (Abramson & Abramson 1999). Cross-sectional and longitudinal surveys are commonly used in epidemiology and community health research to describe and analyse health-related information about a population under study. Most survey instruments, such as health-status questionnaires, are based on self-report. These questionnaires are commonly developed and validated in Europe or the USA. Validation refers to the process of establishing a method is sound: that an instrument measures what it purports to measure (ed. Last 1995). For use in multiple ethnic groups, such questionnaires are then translated into a range of minority ethnic languages (Hunt & Bhopal 2003). This process of translation, however, can be problematic and may represent an ethnocentric and culturally biased viewpoint. Ethnocentrism has been defined as "evaluating other races and cultures by criteria specific to one's own" (*The Concise Oxford Dictionary* 1995). A questionnaire developed in the language of Western biomedicine may not accurately

represent the world-view of minority ethnic groups within Western culture.

Research instruments designed by white middle class health professionals for use in other cultures have been criticised on these grounds (Webster 1997).

Ethnocentrism in health studies and medical science needs to be avoided (Eyton & Neuwirth 1984; Fabrega 1975; Myers 1977). There are two reasons for this: first, because it is discriminatory; and second, because it yields inaccurate and non-comparable data, as described further in Chapter 3. Therefore, steps must be taken to ensure that commonly used survey tools and techniques are both culturally and linguistically appropriate for use in multiple ethnic groups.

Whilst these issues have been topics of study and debate for many years, particularly in domains such as cross-cultural psychology, psychiatry and health measurement, they have been given less consideration in certain biomedical and epidemiological fields. This thesis aims to apply 'state-of-the art' cross-cultural methodology within an epidemiological context. As illustrated in Chapter 3, epidemiological research needs to become more informed about different paradigms and methodologies in order to carry out scientifically sound cross-cultural research on symptoms in different ethnic and language groups. Health survey research is firmly rooted in Western biomedicine and often investigates health states by reducing them to quantitative indices: as Pfeffer (1998, p.1382) has described, "...'facts' are observed and boxes ticked". This approach assumes that health and illness states can be accurately represented by predetermined categories of responses to predetermined

questions. It postulates the existence of separate disease entities, demonstrable organic pathologies, which can occur in isolation from situation, culture or context.

In the case of the Rose Angina Questionnaire, the epidemiological instrument used as a case study in this project, it is assumed that by asking certain diagnostic questions we can determine from an individual's response whether he or she has coronary heart disease, regardless of ethnicity, gender, age, socio-economic status, and other factors that constitute the fabric of an individual's identity. This approach does not acknowledge any distinction between a symptom that is spontaneously reported and an individual's response when asked a question which may or may not have meaning or relevance to them (Wilbush 1985). By equating an individual's response to a question with the presence or absence of a symptom of disease, it is assumed that the individual's response is an accurate reflection of their disease state, when in fact the response may be an artefact of the questioning procedure.

The biomedical epidemiological approach has its strengths; quantitative survey research has provided important insights into patterns of population disease leading to preventive measures and disease control. However, the weaknesses of such an approach are also apparent. Pre-categorising human experience risks rigid reductionism, and assumes uniformity of perception, interpretation and response to a question. In relation to the Rose Angina Questionnaire, it is assumed that angina is an objective phenomenon based on an underlying clinical reality.



This may not be the most appropriate paradigm to operate within when considering the validation of cross-cultural measures of health status. Alternative ways of conceptualising the world have developed in response to the mechanistic and essentialist tradition of Western biomedicine. Social constructivism, for example, argues that the social and cultural world is constructed by the actors within it, and that the terms by which the world is understood are social artifacts (Schwandt 1994). Health and illness beliefs and experiences are part of this constructed social world. Thus health is a socially defined construct and cannot, therefore, be viewed as independent from the form of society in which it is studied (Engel 1980; Kellman 1975; Kleinman 1977, 1987; Kleinman, Eisenberg, & Good 1978; Koo 1987; White 1982; Wilbush 1985). Social constructivists also regard language as a fundamental component in the collective generation of meaning within a culture. In order to understand a concept it is necessary to investigate this process of meaning construction and how it is embodied in the culture's language. In the case of the Rose Angina Questionnaire, it would follow that it is important to speak to people in their own language about the subject under enquiry.

The epidemiological necessity for a cross-culturally valid angina screening instrument has both philosophical and practical implications. This project will examine these implications. Firstly, the underlying assumptions of epidemiology are challenged by deconstructing them within a cross-cultural context. Secondly, current methodology in cross-cultural cardiovascular survey research is examined and assessed for appropriateness. Thirdly, the challenges of carrying out qualitative field research in a range of different languages are investigated.

A fundamental tenet of this project is cultural relativism, i.e. respecting each culture's conceptualisation of the world as equally valid. It has been argued that sections of a population have a privileged and dominant world-view which is seen as more legitimate than dominated or muted groups (Ardener 1975, cited in Coffey, Holbrook, & Atkinson 1996), such as women, lower classes, or minority ethnic groups. Muted groups are categorised according to the systems of the dominant group and are reduced to the subjugated and muted objects of a dominating discourse. This thesis argues that it cannot be assumed that survey instruments developed within the dominant biomedical discourse are appropriate for use in other cultures, and seeks to carry out participatory research within ethnic minority communities in order to allow their world-view to emerge. This research incorporates elements from several disciplines- epidemiology, sociolinguistics, medical sociology, and translation theory. The challenge is to integrate these different paradigms into a cohesive whole. It should be emphasised that this was an exploratory study designed to assess the feasibility of using an epidemiological questionnaire in a range of different languages and cultures (see Chapter 4 for a discussion on the evolution of this aim), and not an in-depth medical sociological study. The consequences of this emphasis are described further in Chapter 8.2.

A further challenge to be considered is the carrying out of research in languages other than those spoken by the researcher, which necessitates working with and through bilingual project workers, and raises issues around control of the research process.

In Chapter 2, the issues surrounding ethnicity and coronary heart disease in Britain are discussed. The development and history of the Rose Angina Questionnaire are described, the reasons for studying it in a cross-cultural context are explained, the literature on its cross-cultural use is reviewed and the fact that further research is required is established. In Chapter 3, previous research on cross-cultural adaptation of questionnaires is reviewed in order to extract key theoretical principles and methodological steps. The appropriateness of qualitative research for this type of enquiry is illustrated. The issue of symptom perception in different cultures is discussed further, with an emphasis on pain perception, interpretation and reporting. The main and subsidiary aims and research questions of this project are stated and the research methods used are detailed in Chapter 4. Substantive findings emerging from the interview study are presented in Chapters 5, 6 and 7. In Chapter 8, the study's results and the impact of the methodology used in carrying out this type of research in the future are discussed. A contextualisation of the project and conclusion are provided, with recommendations for further work.

## **Chapter 2      Ethnicity, coronary heart disease, and angina measurement in epidemiological studies**

## **2.1 A multiethnic Britain**

Ethnicity is broadly defined as:

"...shared origins or social background; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group; and a common language or religious tradition" (Senior & Bhopal 1994, p.327).

In the 2001 census, 8.1% of the population identified themselves as belonging to one of the minority ethnic groups (including 'mixed' and 'Irish'). South Asians (including Indians, Pakistanis and Bangladeshis) constituted 3.6%, 'Black' ethnic groups (Black-African and Black-Caribbean) 2.0%, and Chinese 0.4% of the British population. Table 2.1 shows the percentages and total populations of each ethnic grouping in England, Wales and Scotland, at the time of the 2001 census (Gill et al. in press and online). As can be seen, the size of the ethnic minority population in Scotland was 2% (just over 101,000) of the total population, and the largest ethnic minority groups are Pakistani, Chinese and Indian.

	Great Britain	England & Wales	England	Wales	Scotland
White	91.9	91.3	90.9	97.9	98.0
Ethnic Minorities	8.1	8.7	9.1	2.1	2.0
Mixed	1.2	1.3	1.3	0.6	0.3
Black	2.0	2.2	2.3	0.2	0.2
<i>Black-Caribbean</i>	1.0	1.1	1.1	0.1	0.0
<i>Black-African</i>	0.8	0.9	1.0	0.1	0.1
South Asian	3.6	3.9	4.1	0.8	1.0
<i>Indian</i>	1.8	2.0	2.1	0.3	0.3
<i>Pakistani</i>	1.3	1.4	1.4	0.3	0.6
<i>Bangladeshi</i>	0.5	0.5	0.6	0.2	0.0
Chinese & others	1.3	1.3	1.4	0.5	0.6
<i>Chinese</i>	0.4	0.4	0.4	0.2	0.3
Total population	57103927	52041916	49138831	2903085	5062011

**Table 2.1: 2001 census data showing ethnic composition of Great Britain and regions**

In addition, there are refugees and asylum seekers living in Britain and Scotland. In 1996, there were 28,000 applications (mainly from people from Nigeria, India, Somalia, Pakistan and Turkey) for asylum in the UK, of which 2,200 were granted asylum and 5,100 exceptional leave to remain (The British Council 1999). In

Scotland, this group includes people originating in Afghanistan, Sri Lanka, Iraq, Iran, Bosnia and Kosovo, Sudan, Somalia, Russia, Estonia and Chile (Macaskill & Petrie 2000). In 2003, there were an estimated 3,000 asylum seekers and refugees in Lothian and 13,000 in Glasgow (Raj Bhopal, personal communication).

The majority of the ethnic minority population live in the urban areas of Britain, with clustering in the South East and the West Midlands of England (Gill et al. in press; The British Council 1999). As in the rest of Britain, the ethnic minority population in Scotland is concentrated in the main cities, with 1 in 3 of all ethnic minorities living in Glasgow. The lowest percentages of ethnic minorities are found in the more rural areas of the Borders, Shetlands, Western Isles and Orkney (Dalton & Hampton 1994). The Chinese population is represented in all areas of Scotland (Bailey, Bowes, & Sim 1997).

## **2.2 Ethnic variations in coronary heart disease**

Several studies have indicated ethnic variations in disease in Britain. One of the most pronounced variations reported has been for cardiovascular disease (CVD), particularly coronary heart disease (CHD) mortality. People of South Asian origin (Indian, Pakistani, Bangladeshi and Sri Lankan) living in England and Wales have about 40-50% higher mortality due to coronary heart disease than people of European origin; people of Chinese, Afro-Caribbean and African descent have lower CHD mortality rates (Balarajan 1991, 1996; Gill et al. in press; Wild & McKeigue 1997). However despite the variations in relative mortality, CHD is still one of the major causes of death in all ethnic groups and therefore of key public health

importance (Wild & McKeigue 1997). Data from England and Wales almost certainly apply in Scotland as well. The risk factor profile of the South Asian population in Scotland (Williams, Bhopal, & Hunt 1993) suggests that this population is also at high risk of CHD, and that South Asian women may be at particular risk.

This pattern of increased CHD mortality in immigrant South Asian populations is found in other industrialised countries (Gupta et al. 2002). However, in the country of origin, the mortality rates are not as high as in the country of immigration (McKeigue 1989). In addition, within the country of origin, CHD has been found to be up to 2.5 times more common in urban than in rural areas (Gupta & Malhotra 1975).

The underlying reasons for these ethnic variations in CHD are incompletely understood and do not appear to be explained solely by variation in the classic cardiovascular risk factors such as hypertension, smoking and cholesterol (Gill et al. in press; Gupta et al. 2002). It has been stated that:

"The relationship between migration and health is a complex one, which includes genetic, social, economic and cultural elements." (Bollini & Siem 1995) p.820.

Some researchers have suggested that the main reasons for ethnic variations in health are structural factors such as poverty, social exclusion and direct and indirect racism. For example, it has been argued that material factors make a "key contribution to differences in health between different ethnic groups" (Nazroo 1998, p.172). In the case of coronary heart disease, there is evidence that amongst the South Asian



populations it is the poorest groups, the people of Pakistani and Bangladeshi origin, who suffer the highest CHD rates compared to the relatively affluent Indian-origin population (Bhopal et al. 1999). However, it has been concluded that social class is not sufficient explanation for the patterns of excess mortality among British South Asian men and there is a need to look at other explanations for ethnic variations in mortality (Harding & Maxwell 1997). An alternative theory is that CHD in adult life is a result of foetal development and growth (the foetal origins hypothesis) (Barker 1995). Genetic reasons for ethnic variations have also been suggested.

In summary, the theories advanced to explain ethnic variations in CHD mortality are divided into five main groups (eds. Patel & Bhopal 2004):

1. genetic background and phenotypic expression
2. growth and development (particularly in early life)
3. physical environment
4. economic and social environment
5. behaviour.

The study of the health of immigrant populations in Britain offers a rich resource for the exploration of CHD aetiology and risk factor-outcome relationships. Such questions are best investigated via large epidemiological cohort studies (Bhopal 2002b). This project examines cross-cultural survey research, in which health status is measured and compared between populations.

### **2.3 Angina measurement in multi-ethnic surveys**

One important measure in such surveys is that of coronary heart disease prevalence or population morbidity, i.e. the number of living people in the population suffering from the disease. Angina pectoris is one of the manifestations of CHD morbidity. Measuring the prevalence of angina in a population is a proxy for CHD prevalence. There are various ways of assessing angina prevalence. The Black and Minority Ethnic Group second health and lifestyle survey (Health Education Authority 2000) asked participants "Have you ever been told you suffer from angina (/heart attack)?". The Health Survey for England (HSE)1999 (eds. Erens, Primatesta & Prior 2001) asked participants if they had ever suffered from angina, and if so, if they had ever been told they had the condition by a doctor. Table 2.2 shows the ensuing HSE data on self-reported angina prevalence and the age-standardised risk ratios in a range of ethnic groups in England.

<b>Prevalence of angina</b>	<b>Black Caribbean</b>	<b>Indian</b>	<b>Pakistani</b>	<b>Bangladeshi</b>	<b>Chinese</b>	<b>Irish</b>	<b>General population</b>
<b>Men</b>							
Observed %	1.9	5.4	2.9	3.9	1.8	4.8	5.3
Standardised risk ratio	0.32	1.28	1.26	1.86	0.38	1.06	1
<b>Women</b>							
Observed %	2.2	1.7	1.5	1.3	0.4	2.9	3.9
Standardised risk ratio	1.11	0.95	1.26	1.09	0.20	0.94	1

**Table 2.2: Angina prevalence and standardised risk ratio in ethnic groups in England**

Rather than asking individuals for a self-reported history and doctor's diagnosis of angina or heart disease, an alternative measure of angina is the Rose Angina Questionnaire (RAQ) (Rose 1962), the most commonly used population measure of CHD morbidity. As described in the next section, this questionnaire has been shown to perform inconsistently in different ethnic groups in England (Fischbacher et al. 2001) and to yield different angina prevalences (eds. Erens, Primatesta & Prior 2001) than those elicited by the self-reported diagnoses shown above. As accurate indicators of CHD prevalence rates are vital for the collection of meaningful information on patterns of CHD in Britain's multiethnic community, it is clear that the cross-cultural validity of this questionnaire needs to be ascertained before robust quantitative epidemiological research can be carried out. This research project investigated the feasibility of producing a cross-culturally valid version of the Rose Angina Questionnaire for use in multi-ethnic surveys.

## **2.4 The Rose Angina Questionnaire: development and versions**

Angina pectoris is one of the clinical manifestations of heart disease. There are approximately 1.8 million patients with angina in the United Kingdom (Lewin et al. 2002). As mentioned, for epidemiological purposes a screening instrument is necessary to estimate population prevalence of angina (a proxy for CHD prevalence). Such an instrument, the WHO (Rose) Angina Questionnaire (RAQ) was developed by Geoffrey Rose in 1962. In its basic form, it is a seven-item questionnaire that defines angina as chest pain that limits exertion, is situated over the sternum or in the left chest and left arm, and is relieved within ten minutes by rest. It was originally developed as an interview-administered tool. The sample on which the questionnaire

items were developed was small and highly selected. Hospital patients from three groups- 36 (30 men and 6 women) known to be suffering from angina pectoris, 15 men who had myocardial infarction but not angina, and 23 (20 men and 3 women) with chest pain due to non-cardiac causes- were asked to fill out a 'fact-finding' questionnaire. This aimed to elicit symptoms that would distinguish patients with angina from those without. The RAQ was the outcome of this process. Ethnicity of the hospital patients was not reported, but they were all English-speakers. Validation (by comparison with physician diagnosis) was carried out by interviewing 57 American men with chest pain. Subsequently several modifications of the original RAQ have been used (Rose 1962; Rose et al. 1982); for example, a self-report measure (Lundman et al. 1971; Rose, McCartney, & Reid 1977) and a postal version (Cederlof, Jonsson, & Lundman 1966; Hagman, Jonsson, & Wilhemsen 1977). A version with supplemental questions has also been developed to identify individuals with atypical symptoms (Bass, Follansbee, & Orchard 1989). Table 2.3 shows the items on the RAQ, for administration by an interviewer.

1. **Have you ever had any pain or discomfort in your chest?** (yes/ no)
2. **Do you get this pain or discomfort when you walk uphill or hurry?** (yes/ no/ never hurries or walks uphill)
3. **Do you get it when you walk at an ordinary pace on the level?** (yes/ no)
4. **What do you do if you get it while you are walking?** (stop or slow down/ carry on)
5. **If you stand still, what happens to it?** (relieved/ not relieved)
6. **How soon?** (10 minutes or less/ more than 10 minutes)
7. **Will you show me where it was?** (sternum, upper or middle/ sternum, lower/ left anterior chest/ left arm/ other)

Angina is defined as being present in participants who answer:

1: yes; 2 or 3: yes; 4: stop or slow down; 5: relieved; 6: 10 minutes or less; 7: either  
a) sternum (upper or middle, or lower) or b) left anterior chest *and* left arm

### **Table 2.3: The Rose Angina Questionnaire**

The RAQ yields an assessment of definite Rose angina (i.e. angina diagnosed by RAQ) if the answers to all seven questions are those described at the bottom of the above table. In addition, an assessment of possible Rose angina refers to exertional chest pain (answers 'yes' to questions 1 and 2) in the absence of the remaining criteria for definite Rose angina.

## **2.5 General research with the Rose Angina Questionnaire**

### Validity

Despite the highly selected nature of the development sample, the RAQ has been extensively reported to be valid in other populations (Fischbacher et al. 2001). Most validation studies use either a doctor's diagnosis or clinical criteria (e.g. electrocardiographic findings, exercise thallium scintigraphy, coronary arteriograms etc) for the presence of CHD against which to assess outcome on the RAQ.

### Gender

RAQ validity may not be similar in men and women. In epidemiological studies, angina as measured by the RAQ has been shown to be more common in women than men (Kannel & Feinleib 1972; Langford et al. 1984). However, there may be gender differences in reporting of symptoms of angina (Harris & Weissfeld 1991). For example, one epidemiological study on 10,000 twin-pairs (Cederlof, Jonsson, & Lundman 1966) yielded 11 cases of women with RQ angina. None of these women had this diagnosis confirmed at clinical examination; three other women, with clinically diagnosed angina, did not show a positive questionnaire response. These findings contrast with those in men, where a good association between RAQ diagnosis and clinical diagnosis was observed. Other studies confirm that the presence of Rose angina in women is less likely than in men to correlate with ECG changes, doctor diagnosis, or mortality (Langford et al. 1984; Reunanen et al. 1983; Rossouw et al. 1984; Wilcosky, Harris, & Weissfeld 1987). In contrast, some studies have shown an association between Rose angina and long-term cardiovascular

mortality in women (Campbell et al. 1984). The appropriateness of the RAQ for women is therefore not clear.

### Prognostic value

Rose himself discussed the prognostic value of the RAQ and concluded that it was a useful tool for identifying people at high risk of heart disease (Rose 1965). One study found that people who reported the symptoms of Rose angina were three times more likely to die from cardiovascular disease than those who did not report Rose angina (Feinleib et al. 1982).

However, other studies have shown a confused relationship between symptom reporting, Rose angina and subsequent verifiable cardiac events. For example, men and women without CHD, as confirmed by coronary angiography, reported more chest pain symptoms than people with CHD (Greene, Schocken, & Spielberger 1991). In addition, one study found that the RAQ as a diagnostic tool was not predictive of subsequent clinical events among hypertensive patients (Madhavan, Cohen & Alderman 1995).

### Definite and possible Rose angina

It has been shown in a general population sample of white middle-aged men that chest pain on exertion (possible Rose angina) was as likely to predict subsequent coronary events as definite Rose angina (Cook, Shaper, & Macfarlane 1989).

Amongst 8359 elderly people in the U.S.A., the risk of CHD mortality over 3 years



for those who reported exertional chest pain was at least as high as for those who reported definite Rose angina (LaCroix et al. 1990).

### Repeatability/ reliability

Whilst some researchers have reported that RAQ responses have sufficiently good repeatability (the extent to which the results of the questionnaire are similar each time it is administered) (ed. Last 1995) to allow reliance on a single report in epidemiological studies (Sorlie et al. 1996), others have found evidence of low repeatability of results (Hagman, Jonsson, & Wilhemsen 1977). For example, Rose himself found that the point prevalence underestimates the true prevalence in relation to the degree of variability in symptom reporting (Rose 1968) and recommended repeated administrations of the questionnaire. One study found that, five years after an original diagnosis of RAQ angina, 20% of the participants reported that they had never experienced chest pain (Medalie et al. 1973).

### Modes of administration and variation in versions used

There is substantial variation in data generated by different versions of the RAQ. For example, it has been reported that self-administration yields a prevalence of angina that is about twice as high as that yielded by the interviewer-administered version (Rose, McCartney, & Reid 1977). In addition, there is much variation in the different versions of the RAQ used in different studies. For example, the RAQ has been modified for use as a postal questionnaire (Cederlof, Jonsson, & Lundman 1966) and expanded for use in a clinical examination (Hagman, Jonsson, & Wilhemsen 1977). Examination of these versions reveals important differences in

question wording and format compared to Rose's original. Clearly, this may influence responses. For example, one study modified the questionnaire to include chest pain brought on by 'emotional stress' (Medalie et al. 1973) as well as addition of other questions not in the original.

### Age

There is also a confusing picture of age-related prevalences as yielded by the RAQ. Whilst some studies have reported a uniform increased prevalence of angina with age in both men (Abernathy et al. 1988) and women (Krogh et al. 1991; Wilcosky, Harris, & Weissfeld 1987), others suggest that risk of angina decreases with age (Smith et al. 1993).

### Sensitivity and specificity

Depending on the reference standards and populations used, varying sensitivity (the extent to which a method gives a true positive rate) and specificity (the extent to which a method gives a true negative rate) (Bhopal 2002a) have been reported for the RAQ (Rose et al. 1982). Generally, the specificity has been found to be relatively high but the sensitivity variable (Fischbacher et al. 2001). For example, Rose (1962) found that the RAQ yielded a relatively high sensitivity of 83% and high specificity compared to clinical examination; the Whitehall study reported a sensitivity of 10% and a specificity of 97% of the RAQ for CHD deaths during 10 years of follow-up (Bulpitt et al. 1990); and, in a sample of 198 patients, a supplemented RAQ was found to have 26% sensitivity and 79% specificity (Bass, Follansbee, & Orchard 1989).

### Epidemiological utility

Regardless of the above discrepancies, it is important to remember that the RAQ is an epidemiological and not a diagnostic tool. Epidemiological criteria for establishing disease need to be simple enough for use on a mass scale, objective, repeatable and descriptive; clinical criteria are interpretative, focussed on individual diagnosis and more all-inclusive (Rose et al. 1982). The Rose Angina Questionnaire, whilst being imperfect diagnostically, is the best population measure of CHD prevalence in use.

### **2.6 Use of the Rose Angina Questionnaire in different ethnic groups**

In order to investigate ethnic variations in coronary heart disease, it is important to have versions of the RAQ which are valid across cultures and languages; i.e. versions of the RAQ that are similarly effective in measuring angina in different cultural and language groups. Researchers applying the RAQ internationally have speculated on whether the angina prevalences yielded were due to absolute variations in underlying disease processes or whether they were due to different symptom reporting between groups or varying understanding of the questions (Abernathy et al. 1988; Feinleib, et al. 1982). Rose himself warned that "cultural differences...might bias the outcome" (Rose, McCartney, & Reid 1977, p.47) and a subsequent suggestion has been made by Keen (Keen & Jarrett 1979, p.193) that angina prevalence by RAQ should be "viewed in the light of cultural differences between national groups that might affect the perception of standard questions".

For example, whilst one study found that black men in the USA had a higher prevalence of RAQ angina than white males, and black women had higher prevalence of RAQ angina than white women (Langford et al. 1984), another study found that African-American respondents were less likely to score positively for RAQ angina than white respondents (Raczynski et al. 2001). The authors concluded that there were possible ethnic differences in both symptom awareness, and the need to seek treatment for symptoms. Another study investigated whether blacks and whites differed in reporting Rose angina (Smith et al. 1993). However, the responses were gathered both by telephone interview and face-to-face interviews, and the differing modes of administration and visible ethnicity of the questionnaire administrator may have had an impact on the response. The researchers found that black participants were more likely to report angina if they felt that they were not getting the medical care they needed. This indicates that factors other than objective pathology can influence RAQ response. There are a small number of studies looking specifically at RAQ performance in different cultures or languages and there is evidence that the RAQ may have varying validity in different cultural or ethnic groups. For example, one study concluded that the RAQ had shown good utility for white men but more variable utility among Latino, African-American and female subjects (Haywood et al. 1993). Another found that the RAQ was of dubious validity in rural Jamaica as respondents appeared either not to understand the questions correctly, misinterpreted the intent of the interview, and were anxious to respond in a way acceptable to the researcher (Ashcroft 1976).

The prognostic value of Rose angina also varies with ethnicity and gender (LaCroix et al. 1989). It has been shown that whilst Rose angina was strongly predictive of subsequent coronary events and mortality in white men, white women and black men, there was no such correlation in black women (Langford et al. 1984). For Chinese samples, it has been found that Rose angina correlates poorly with some cardiovascular risk factors (Chen et al. 1996). This paper also questions the relevance of ECG findings in the Chinese. Another study (Mitchell et al. 1991) suggests that Mexican-American men experience high rates of angina despite low rates of myocardial infarction.

In Britain, the cross-cultural validity of the RAQ has also been questioned. For example, in addition to reporting angina prevalence across ethnic groups based on self-report of a diagnosis of angina (see previous section), the Health Survey for England 1999 (eds. Erens, Primatesta & Prior 2001) also reported angina prevalence based on Rose Angina Questionnaire outcome. It was found that the differences in angina prevalence between ethnic minorities and the general population were smaller when measured with the RAQ. The fact that different responses were elicited by RAQ and reports of diagnosed angina led the researchers to speculate that these differences may be due to "cultural differences in identifying and/or describing the symptoms" (Volume 1, p. 66).

Following their comparison of the methods used to assess coronary heart disease prevalence in British South Asians, Patel et al (1997, p.210) have made the suggestion that the RAQ be further investigated for use in the UK's ethnic minorities:

"(T)he applicability of [CHD] conventional survey methods in [the South Asian] population is unknown...current epidemiological methods for assessing CHD prevalence may be inaccurate in South Asians, especially women."

This issue was further addressed by the Newcastle Heart Project (NHP) (Bhopal et al.1999), a cross-sectional study of a number of ethnic groups (European, Chinese, South Asian) in which a range of psychosocial, physiological, lifestyle and screening measures were recorded. The RAQ in this case had been subject to a forward and backward translation by bilingual researchers in each of the relevant languages. Subsequent conferring between the bilingual researchers produced final versions that were interview-administered. As illustrated in Table 2.4, analysis of the RAQ responses in the European and South Asian groups (Indian, Pakistani and Bangladeshi) indicated that the performance of the Rose Angina Questionnaire was not consistent. RAQ responses showed inconsistent agreement with other measures of angina, such as electrocardiograph (ECG) findings and doctor's diagnosis across ethnic group (Fischbacher et al. 2001).

<i>WOMEN</i>	<b>Definite Rose angina</b>		
	European	South Asian	Difference (95% CI)
<b>Agreement with doctors diagnosis of angina (Kappa)</b>	0.20	0.06	
<b>Test performance</b>			
<b>RQ sensitivity</b>	24%	8%	-16 (-36, 4)
<b>RQ specificity</b>	95%	96%	1 (-2, 4)
<b>Agreement with ECG</b>	0.11	0.02	
<b>Test performance</b>			
<b>RQ sensitivity</b>	33%	6%	-27 (-67, 12)
<b>RQ specificity</b>	94%	96%	2 (-1, 6)

<i>MEN</i>	<b>Definite Rose angina</b>		
	European	South Asian	Difference (95% CI)
<b>Agreement with doctors diagnosis of angina (Kappa)</b>	0.42	0.29	
<b>Test performance</b>			
<b>RQ sensitivity</b>	37%	21%	-16 (38,5)
<b>RQ specificity</b>	96%	97%	1 (-2, 4)
<b>Agreement with ECG</b>	0.19	0.20	
<b>Test performance</b>			
<b>RQ sensitivity</b>	36%	18%	-27 (-67, 12)
<b>RQ specificity</b>	93%	97%	3 (0.2,7)

**Table 2.4: Performance of Rose Angina Questionnaire in European and South Asian men and women**

The NHP researchers concluded:

"The performance of the Rose angina questionnaire was sufficiently inconsistent to warrant further work to achieve greater cross-cultural validity." (Fischbacher et al. 2001, p.1009)

However, it is clear that the rationale that applies to the suggestion that the RAQ may not be cross-culturally equivalent also applies to the two measures used to establish RAQ performance, and indeed applies to any combination of all three. There is evidence that both measures used to establish clinical/ criterion validity-the extent to which the measurement correlates with an external (clinical) criterion of the phenomenon under study (ed. Last 1995)- of angina diagnosis may in themselves have different profiles depending on ethnic group. For example, it has been illustrated that the ECG abnormalities accepted in biomedicine to indicate underlying coronary pathology may not have similar profiles or meanings across ethnic group (Cook, Shaper, & Macfarlane 1989). In all ethnic groups, there is also a clinical diagnosis of 'syndrome X' which describes patients with exertional chest pain in the presence of normal coronary arteries as detected by arteriogram (Sun et al. 2001). Other authors have noted that there may be differing clinical manifestation of CHD across ethnic groups due largely to such variation in coronary syndromes (Clark et al. 2001). A doctor's diagnosis of angina, one of the criteria for establishing RAQ validity, may be influenced by the ethnicity of the patient due to varying experience and/ or presentation of symptoms across ethnic group. For example, it has been found that South Asians are more likely to have atypical chest pain (Feder et al. 2002). The Newcastle Heart Project has also shown a varying presentation of chest pain in different ethnic groups (Fischbacher et al. 2001). Culture influences



symptom perception and doctor-patient interactions and may influence the doctor's assessment (Bhui & Bhugra 2001). Research has shown that clinicians may be subject to bias in the evaluation and treatment of women and minorities with angina (Schulman et al. 1999). There is therefore a need for research to redress the ethnocentric emphasis of the existing RAQ.

## **2.7 Cross-cultural adaptation of the Rose Angina Questionnaire**

Different ethnic, cultural or national groups often require translated versions of a questionnaire for use in a language other than that in which it was developed. In the case of the Rose Angina Questionnaire, it must be translated and adapted from English into the appropriate language.

A basic principle of epidemiology is objectivity of disease measurement. Rose himself cautioned exact standardisation of question wording and interview technique (Rose, McCartney, & Reid 1977), for example:

"Questions must be put to the subject exactly as they are printed: small changes may make unexpectedly large differences." (Rose 1962, p.650)

Given that this referred only to English-speaking interviewers, the possibility for distortion if questions are inadequately or inconsistently translated is greater. This would substantially undermine the validity of between-group findings.

Translation methodology in cardiovascular epidemiology often appears inadequate. For example, many studies, as illustrated later, state only that a lay interpreter administered the questionnaire in the subject's own language. Such lay interpreting is inadequate for epidemiological rigour. It has been shown that medical or clinical

consultations that rely on untrained personnel or lay interpreters show a significant reduction in the efficacy of the encounter due to inappropriate translation. Diagnostic enquiries and responses can be systematically mistranslated and edited by lay interpreters and even simple questions show high levels of inaccuracy. Specific words, particularly anatomical terms, are often mistranslated, for example 'chest' for 'ribs' in Gujarati; translated symptoms caused great difficulty, and technical terms were also poorly translated with some being omitted entirely (Ebdon et al. 1998). Such interactions, be they in a medical consultation or in a questionnaire designed to mimic diagnostic questions, can therefore be misleading. In Chapter 3, more advanced translation and adaptation methodology is described in depth.

Few studies have highlighted the role of translation of the RAQ in influencing the angina prevalence yielded. A Malayam translation of the RAQ in a sample in rural India (Kutty et al. 1993) gave results which showed a conflicting picture between objective (clinical) criteria and RAQ response- the RAQ answers suggested a higher prevalence of CHD in the rural than urban communities, but the objective criteria showed that CHD prevalence was in fact higher in the urban communities. The authors noted that the mismatch in prevalence rates yielded by these two methods might be due to language or translation errors or response bias. However reporting of translation methodology and language issues is often inadequate. For example, an evaluation of an Arabic version of the Rose Angina Questionnaire (Moussa, Gadallah, & Mortagy 1994), despite finding increased sensitivity and specificity in the Arabic version as compared to the English version, did not give any details of the translation process or the form of Arabic used. In order to establish whether studies

using the RAQ had paid appropriate attention to cultural and linguistic issues that may influence response, a more rigorous literature review was carried out.

In collaboration with Dr. Colin Fischbacher (CF) from the University of Newcastle, the author (LH) carried out a review of studies that had used the RAQ in two or more cultural, linguistic or ethnic groups. CF and LH jointly developed the objectives of the review, identified literature search strategies, reviewed abstracts and obtained and appraised published papers. CF maintained and analysed the database of studies reviewed. The objectives were to assess whether international studies using RAQ complied with recommended principles for cross-cultural adaptation of questionnaires (see Chapter 3.4.3), and to assess whether reported angina prevalences from international studies are potentially comparable.

All abstracts from a preliminary literature search of Medline 1966-2001 (1419 abstracts), Embase 1951-2001 (1034 abstracts) and SSC-EXP/SSCI 1981-2001 (630 abstracts) were reviewed to identify papers reporting RAQ results in non-English speaking and/or non-European ethnic groups.

From the citation search, 275 relevant articles citing two key Rose papers ( Rose 1962; Rose, McCartney, & Reid 1977) were identified and copies of 242 (88 %) were obtained. These reported 114 studies in non-English speaking or non-European groups. A standard pro-forma was used (see Appendix 1) to extract relevant data on cross-cultural comparability and study specifics from identified publications.

Retrieval of papers stopped at this stage because of the low yield of studies reporting recommended cross-cultural methodological principles.

It was found that only 12% of the studies reviewed mentioned the language of RAQ administration. Only 18% of studies gave information about ethnicity, and 20% did not include information about the geographical location of the study. Only 4% mentioned translation, and with very little methodological detail, for example:

"the questions were made in Danish" (Andersen et al. 1987, p.173)

"translated into Danish" (Jensen 1984, p.21)

Only 4% mentioned adaptation, although with virtually no information about the process, for example:

"adapted for local use" (Miller et al. 1989, p.809)

"modified after Rose" (Uusitalo, Keyrilainen, & Johnsson 1981, p.54)

There was also wide variation in the mode of administration- 21% of studies used a self-completion version of the RAQ, 32% were administered face-to-face, 3% both, and 45% of studies did not specify which mode of administration was used. The most important finding was that the five biggest studies (n= 29133-57859) (Bjartveit, Foss, & Gjervig 1983; Feinleib et al. 1982; Jonsdottir et al. 1998; Rapola et al. 1996; Tiengo et al. 1996) in non-English speaking ethnic groups gave no details about the cross-cultural adaptation of the RAQ.

Overall, there were no studies reporting methodological work on cross-cultural modification of the RAQ. Only a few papers discuss the applicability of the RAQ in different languages or cultures, but take no steps towards improving its cross-cultural validity. In studies of single non-English speaking or non-European ethnic groups, it was rare for information to be given on language, ethnicity, translation or cross-cultural adaptation. More often clinical or criterion validation (defined above in section 2.6) in the linguistic or ethnic group was described, such as a validation by coronary angiography, mortality rates etc (Cosin et al. 1999; Erikssen, Forfang, & Storstein 1977; Meraji et al. 2000; Patel et al. 1997). In studies comparing angina prevalence in different ethnic/ linguistic groups, it was found that most studies did not specify the cross-cultural adaptation process, and that, as found in studies of single non-English or non-European ethnic groups, priority was given to clinical or criterion validity rather than face or content validity. Face validity refers to a subjective assessment of whether the items on a questionnaire are relevant, reasonable and clear; content validity refers to a more systematic judgement of the extent to which the content of the questionnaire is a logical, balanced and comprehensive representation of the characteristic it is intended to measure (Bowling 2000). This review found that no studies attempted to establish all necessary types of validity. Table 2.5 gives examples of best practice to date. However, these best practice studies failed to establish face and content validity in sufficient depth, by an initial phase of qualitative research in the lay population. This necessity of involving the lay population in the assessment of face and content validity of questionnaires is explored further in Chapter 3.

<b>Author</b>	<b>Linguistic/ ethnic group</b>	<b>Adaptation methodology</b>
<b>Williams et al 1993</b>	Glasgow Punjabis	Translated by educational psychologist, tested, piloted, further discussion
<b>Bhopal et al 1999 Newcastle Heart Project</b>	Gujarati, Hindi, Urdu, Cantonese, Bengali, Hindi	Forward & back translation by bilingual research workers, conferring between workers until agreement reached

**Table 2.5: Best practice in cross-cultural adaptation of the Rose Angina Questionnaire to date**

The translation of the Rose Angina Questionnaire into other languages has been inadequate for the conduct of valid cross-cultural research. There was little methodological consistency between the published papers reviewed, and a lack of transparency about the cross-cultural modification process. Thus, there is no established methodology or exemplar study for cross-cultural adaptation of the Rose Angina Questionnaire. The potential for error is large, leading to the necessity for cautious interpretation of the angina prevalences published internationally.

## **Chapter 3      Cross-cultural health survey research and the Rose Angina Questionnaire**

### **3.1 Chapter overview**

The previous chapter established that the RAQ performs inconsistently across ethnic group. In this chapter, some of the possible explanations for this are examined. To begin, the overlapping relationship between ethnicity, culture and language is discussed. The meaning of cross-cultural validity of survey instruments and the reasons for a lack of cross-cultural validity or comparability are investigated.

Methodological problems with cross-cultural research are summarized.

Recommended principles for carrying out cross-cultural adaptation of a questionnaire are outlined. Some factors influencing symptom perception and symptom reporting across cultures are reviewed and their possible impact on the RAQ response discussed.

### **3.2 Ethnicity, culture and language as variables in epidemiological research**

The term 'ethnicity' is derived from the Greek noun '*ethnos*' meaning nation or people (Sollors 1996, p.x). As mentioned in Chapter 1, it has been described as:

“...shared origins or social background; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group; and a common language or religious tradition” (Senior & Bhopal 1994, p.327)

The problems and potentials of ethnicity as a variable in epidemiological and health research have been written about extensively (Bhopal, Phillimore, & Kohli 1991; Chaturvedi & McKeigue 1994; O'Loughlin 1999). One problem is that there is little international agreement on ethnic categories and those used can mask important heterogeneity within that category. For example, the use of the term 'South Asian' to



denote people originating in India, Pakistan, Bangladesh and Sri Lanka encompasses people of differing nationalities, religions, diets, and many different languages.

Another key problem is that the comparison group often cited, that is, 'white', also covers a diverse range of people, including non-visible minority groups, and masks substantial cultural and health-status related heterogeneity. It has been pointed out that the use of this category in ethnic group classifications for medical research purposes in Britain includes hidden minority populations such as the Irish, Turks and Cypriots, despite these groups suffering similar health-related and structural disadvantage as other minority groups (Aspinall 1998). When census categories are used, mainly relating to ancestral origin, they can conceal important differences in religion, language, culture and place of birth which may not provide sufficiently rich information required for the detailed analysis of health risks in relation to population subgroups (Aspinall 1997).

In addition, there is often a conflation between ethnicity, culture and language and a failure to define the meaning of these terms (Bhui & Bhugra 2001; Pfeffer 1998).

Culture has been described as:

"...a set of guidelines (both explicit and implicit) that individuals inherit as members of a society, that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment" (Helman 2000, p.2).

Helman also illustrates the link between culture and language:

"[Culture]...provides [individuals] with a way of transmitting these guidelines to the next generation- by the use of symbols, language, art and ritual." (p.2)

Language is also a factor in, but does not equate with, ethnicity. Weber (1922) has emphasised the interdependence of ethnicity and language:

“...groups...can engender sentiments of likeness which will persist even after their demise and will have an 'ethnic' connotation....But most directly, such an effect is created by the language group which is the bearer of a specific 'cultural possession of the masses' (*Massenkulturgut*) and makes mutual understanding (*Verstehen*) possible or easier” (in Sollors 1996, p.57)

Culture, ethnicity and language are inextricably interwoven and a specific discipline, ethnolinguistics, studies the relationship between them. Therefore, a central issue when examining the nature of cross-cultural survey research is that of language. In 1996, it was reported that almost three out of four of those born outside the UK were 'below survival level' for functional literacy- for example, more than a third of non-UK born Bengali and Punjabi speakers could not fill out their name and address on a library card application form (Carr-Hill et al. 1996). Above the age of 50, 57% of Chinese people, 67% of Indian people, 46% of Pakistani people and 39% of Bangladeshi people living in England said they could speak English (Health Education Authority 1999). However this self-report may not indicate a level of English-speaking ability that would allow valid responses to a questionnaire administered in English. Particularly in the more elderly ethnic minority populations, many people in Britain would require non-English versions of standard questionnaires, for either self-administration or interviewer-administration, when taking part in health survey research. In relation to the Rose Angina Questionnaire, angina is more likely to be experienced by the older people in a population, and hence the more elderly people from ethnic minorities are likely to require translated versions of the RAQ. Box 3.1 shows the main languages spoken and understood by older people from a variety of ethnic groups living in England.

**Indian women:** 45 % Punjabi, 43 % Gujarati, 8% English, 3% Hindi, 1% Bengali, 1% other

**Indian men:** 41% Gujarati, 30% Punjabi, 19% English, 3% Hindi, 2% Urdu, 1% Bengali, 4% other

**Pakistani women:** 80% Punjabi, 15% Urdu, 3% English, 2% Gujarati

**Pakistani men:** 49% Urdu, 30% Punjabi, 9% English, 9% Sylheti, 2% other

**Bangladeshi women:** 54 % Bengali, 46% Sylheti

**Bangladeshi men:** 56% Sylheti, 42% Bengali, 1% English, 1% Urdu

**Chinese women:** 56% Cantonese, 25% English, 6% Mandarin, 6% Haka, 5% Hokien, 2% other

**Chinese men:** 61% Cantonese, 18% English, 12% Hakka, 4% Mandarin, 4% Hokien, 2% other

**Box 3.1: Main spoken/ best understood language from age 50-74 in Indian, Pakistani, Bangladeshi (Health Education Authority 2000) and Chinese men and women living in England (Health Education Authority 1999)**

However, merely translating a questionnaire into the appropriate language is not sufficient. Different ethnic groups require both culturally and linguistically appropriate questionnaires. A key consideration in the transference of questionnaires such as the Rose Angina Questionnaire, which ask about symptoms or pain across cultures and languages, is whether or not the concept exists in the other culture, and if so, whether it is constructed in the same way and can be translated in such a way as to retain precise meaning across languages.

It has been recognised that the biomedical fields often fail to integrate social scientific knowledge to their best advantage. Pfeffer has stated that:

“Medicine pays little attention to the innovative theories being developed within history, sociology, anthropology, philosophy, and cultural studies about how, when, and why the identities of some individuals and groups are brought under the rubrics of race, ethnicity, or culture.”(Pfeffer 1998)p. 1382)

This thesis evolves from a practical and not a theoretical need: the need for people who do not speak English to have versions of questionnaires in their own language for epidemiological purposes. It therefore focuses on particular language groups.

### **3.3 Study methodology: a theoretical context**

Chapter 2 showed that previous RAQ translation methodology had been inadequate and noted that consultation with monolingual lay populations was necessary to confirm the cross-cultural acceptability and appropriateness of RAQ items. The literature reviewed suggested that qualitative research was an essential precursor to robust quantitative research in a cross-cultural context. It was also illustrated how perception of angina symptoms and response to RAQ questions may vary along both

cultural and linguistic axes between ethnic groups. This study is based on the argument that the best way to address these issues and assess the feasibility of using the RAQ cross-culturally is by carrying out qualitative interviews in the participant's own language.

If performed rigorously, qualitative methods are valuable research tools (Ahern 1999). In recent years there has been an increased emphasis on participatory and qualitative research in the health services (Entwistle et al. 1998; Mays & Pope 2000; Pope, Ziebland, & Mays 2000) and medical fields (Britten 1995). From primary care to research underpinning clinical trials, the public is being asked to be actively involved in speaking about their health and the care they receive. Rich, deep data is generated and primacy afforded to the experiences of individuals. These patient-centered priorities are also appropriate in examining the validity of survey research in a cross-cultural context in Britain. Qualitative methods are particularly useful in probing cultural beliefs and behaviours whilst minimising assumed shared knowledge since they are designed to elicit participant-centered information about the individual's beliefs, opinions, experiences and attitudes (Curtis & Lawson 2000; Greenhalgh, Helman, & Chowdhury 1998; Nevid & Maria 1999; Oakley 1999; Pfeffer & Moynihan 1996; Sensky 1996). Information gathered via qualitative and community-based methodologies is invaluable in producing a culture-sensitive survey tool, whether for use in a culture-specific research or in cross-cultural comparability studies. In-depth qualitative approaches allow the researcher to grasp the concepts and constructs in the field under enquiry. Such methods can therefore

be usefully employed to address whether the assumptions inherent in the cross-cultural survey use of a particular instrument are valid.

In research focussing on ethnic groups,

"the rigour and appropriateness of the methods chosen is all important in determining the credibility of the findings" (Webster 1997, p.218).

In health-related survey research, participatory involvement of ethnic communities being studied is recommended and increases the relevance and acceptability of the findings (Goodare & Lockwood 1999; Israel et al. 1998; Macauley et al. 1999; Montero 1977; Myers 1977). Qualitative methods are the best way of eliciting people's views, beliefs and perceptions, and have been used with success in studies investigating health beliefs in ethnic minorities. For example, qualitative methods have been used in the Chinese population to investigate a range of phenomena such as contraception (Wiebe et al. 2002); diet, acculturation and health (Satia et al. 2000); and cervical screening (Twinn & Cheng 2000). The researchers heading a qualitative focus group and interview-based study on diet and health in the Chinese emphasised that this qualitative groundwork was important for the subsequent design, implementation and evaluation of dietary interventions in the Chinese (Satia, et al. 2000).

Atkinson et al (Atkinson et al. 1994) carried out a review of the disadvantages and advantages of qualitative methodology in health research specifically with South Asian communities. They concluded that quantitative work on the health of ethnic minority communities has often been carried out without taking a lay perspective

into account, and that a variety of qualitative methods are appropriate for investigating cultural norms and gaining a understanding of ethnic minority cultures.

An important distinction between quantitative and qualitative research phases is the issue of differential generalisability. In quantitative research the methods and sampling procedures are concerned with statistical generalisations. Conversely, qualitative research yields analytic generalisations, which consider how the selected cases fit with general constructs (Curtis et al. 2000). In addition, qualitative research can have

"an emphasis on local context and applicability which can expedite responsive change" (Kai & Hedges 1999, p. 16).

### **3.4 Cross-cultural adaptation of questionnaires**

#### **3.4.1 Background**

In health survey research designed to compare groups, it is crucial that differences in questionnaire outcomes reflect real differences in health status. If questionnaires are translated and modified inappropriately, the results yielded can be artefactual (Berkanovic 1980; Salber & Beza 1980). There are two approaches to producing a questionnaire for cross-cultural survey research. Firstly, a measurement instrument is developed simultaneously in different cultures. This is known as an inductive or parallel approach, as exemplified by the World Health Organisation Quality of Life project (The WHOQOL group, 1998). Secondly, a questionnaire developed in one culture is adapted for use in another culture (the deductive or sequential approach questionnaire development). This latter form is by far the most common, and is most open to ethnocentric distortion.



The literature shows a proliferation of cross-cultural survey research in the past few decades, particularly in fields such as 'health-related quality of life' (Hunt 1998), and steps have been taken to develop robust cross-cultural methodology in certain fields. Nevertheless, it has been noted that there is still a need for an increase in the reliability -the stability of a measurement when repeated under the same conditions (ed. Last 1995)- and the cultural appropriateness of both existing data collection instruments and of assessment of the data collected (Pasick et al. 2001). In order for a questionnaire to be cross-culturally valid, it must be equivalent in each group. The term equivalence has multiple meanings; a recent review (Herdman, Fox-Rushby, & Badia 1997) found that 19 different types of equivalence were commonly described in cross-cultural methodological studies and these were established in varying and inconsistent ways. The four principle types of equivalence are summarised below (Herdman, Fox-Rushby, & Badia 1997,1998; Keller et al. 1998).

*Lexical* equivalence refers to the words in different languages relating to the same subject.

*Conceptual or cultural* equivalence refers to whether the construct being investigated is salient and relevant to the target population, and reflects the culture's worldview, shaped by linguistic, environmental, historical, biological and other factors.

*Functional* equivalence relates to the purpose or significance of the behaviour; an apparently similar behaviour can have different meanings across cultures.

*Metric* equivalence applies to scalar questionnaires and relates to the relationship between the variables, which can vary across cultures.



### **3.4.2 Problems with cross-cultural adaptation methodology**

#### *1. Translation of questionnaire from one (source) language to another (target) language*

A simple forward and back translation technique can be used to render the original version of the questionnaire into another language. This approach has serious flaws, in that it may demonstrate a spurious lexical equivalence whilst neglecting to assess whether questionnaire items are meaningful, relevant, acceptable and sufficiently broad to cover the issue in the culture or language being studied (Deutscher 1973; Hunt 1993). This simple forward-back translation technique has been shown to be problematic in practice in health studies and it has been recommended that it is supplemented with extensive discussion and comment (Small et al. 1999a).

Establishing lexical equivalence by basic translation techniques, whilst neglecting to establish the other forms of equivalence as outlined above, may not produce cross-culturally valid versions of standard questionnaires.

In addition, the adapted questionnaires are commonly translated by unrepresentative bilingual people, such as health professionals of differing socioeconomic, educational, age, gender and linguistic status than the wider ethnic population.

Bilingual people will often translate into the high form of a language rather than an idiomatic or colloquial form (Hendricson et al. 1989; Hunt 1998). This can be problematic if no feedback from lay people is incorporated in the process. However, lay people monolingual in the target language are rarely involved in the assessment

of the meaningfulness of the translations or the applicability of the questionnaire (see next section, 3.4.3).

## *2. Questionnaire items*

It should not be assumed that minimal adjustment to the wording of a questionnaire makes it valid in populations other than those in which it was originally developed. There are nuances of meaning associated with different words and items within a cross-cultural health questionnaire that can systematically bias the response by ethnic, cultural or linguistic group.

In addition, much research has confirmed that ethnicity is an important factor in the conceptualisation of health and illness. A key consideration in the transference of questionnaires about symptoms or pain across cultures and languages is whether or not the concept exists in the other culture, and if so, whether it is constructed in the same way. Therefore, careful translation may not be sufficient to transfer a research instrument from one culture to another (Deyo 1984; Hendricson et al. 1989). As mentioned above, translation alone may only establish lexical equivalence and does not establish conceptual or cultural equivalence. Non-salience or inappropriateness of items, or the omission of culture-specific items can also contribute to reported differences (Hunt 1998). For example, when adapting the Nottingham Health Profile for use in an Arabic-speaking population, it was found that items querying emotional state were deemed too intimate to be appropriate for use in the particular subgroup of Egyptian respondents (Hunt, McEwan, & McKenna 1986).

The concept of the 'category fallacy' refers to misrepresentation of response due to variation in cultural understanding of a concept (Kleinman 1977). This bias results from failure to distinguish between universal concepts accepted across multiple cultural groups ('etic' or universal phenomena), and concepts which have meaning only within a specific cultural group or context ('emic' phenomena) (as discussed by Berry 1969, 1989). It may also be the case that some questions cannot be made equivalent in all cultures to be studied, and hence some questionnaires may benefit from a core list of questions that are valid across multiple ethnic/ language groups, with an additional list of supplemental questions that are culture-specific.

### 3. *Response categories*

Non-ambiguous, salient and conceptually equivalent questionnaire items are not the only basic requirements of an accurate and culturally valid second language version of a questionnaire. It is also vital to consider the issue of comparability of response formats. As Moore has cautioned,

"A well known disadvantage of questionnaire research is that available response categories may not reflect subject response preference but... the *a priori* biases of the researcher. The investigator may also apply another set of meanings than the patient intends to the same verbal expressions" (Moore 1990)p.172

Semantic nuances and distinctions can create problems when responses are coded into predetermined categories in order to facilitate comparisons. For example, even a simple affirmative or negative response can contain different cultural connotations (Deutscher 1973). Individuals also respond with regard to a culturally normative reference group. Social comparison theory argues that people from a specific culture respond to a question by comparing themselves with others within their culture. These standards of comparison can vary between cultures and can confound cross-

cultural comparison of questionnaire responses (Heine et al. 2002). Culturally mediated differences in cognition and interpretation are now regarded as responsible for many of the systematic differences that have been observed in cross-cultural surveys (Warnecke 1997). The researcher also needs to be aware of the conventions governing response behaviour in different cultures. Varying degrees of deferential attitudes to health care professions or questionnaire administrators may provide distorted responses. There is also evidence that people will give an answer to a culturally irrelevant or incomprehensible question in order not to reveal their lack of understanding (Warnecke 1997). This indicates that sound cultural investigation and awareness is required.

#### *4. Questionnaire design*

In terms of questionnaire design, a dual language format can be more effective in ensuring understanding, as people with some degree of bilingual ability will be able to double check a question in both languages (Hendricson et al. 1989).

### **3.4.3 Principles of cross-cultural adaptation methodology**

The principles of cross-cultural research have been summarised by Hunt:

“[When] taking a questionnaire and adapting it for use in several languages and cultures in order to compare or aggregate data across cultures... an absolute requirement... is that both the items on the questionnaire and the responses to them are conceptually and functionally equivalent in every language and culture concerned... and that the underlying concept is present in and salient to the populations of all participating countries.” (Hunt 1998)p.53

Most of the extensive work done to date on projects with specific means of attaining cross-cultural validity has been carried out in the area of health-related quality of life

(Chwalow 1995; Guillemin, Bombardier, & Beaton 1993; Herdman, Fox-Rushby, & Badia 1997, 1998; Hunt 1994; Warnecke et al. 1996) . The sequential International Quality of Life Assessment (IQOLA) project is one of the most extensive examples of cross-cultural research in multiple ethnic (national) groups. This multi-country study has adapted and validated a pre-existing general health status scale, the Short Form-36 (SF-36), for use in over 15 countries, e.g. (Bullinger et al. 1993; Bullinger et al. 1998; Gandek & Ware 1998; Leplege et al. 1998; Perneger, Leplege, & Etter 1999; Sanson-Fisher & Perkins 1998; Sullivan & Karlsson 1998; Wagner et al. 1998; Ware et al. 1995; Ware & Gandek 1998b; Ware & Gandek 1998a). The IQOLA proposed three main methodological steps. Firstly, a reiterative translation and modification procedure to ensure conceptual equivalence and salience in the target culture. Secondly, the assessment of the psychometric properties (such as internal consistency and item-to-scale correlations) of the adapted instrument using formal standardised techniques. Thirdly, for use in large-scale surveys within countries or cultures, the use of normative studies to provide specific population norms and guidelines for accurate interpretation. The following box encapsulates the recommended minimal and optimal principles of cross-cultural questionnaire adaptation as previously suggested by some specialists in this field (e.g. Bullinger et al. 1993).

### *Minimal*

- forward and back translation in each language
- test of psychometric criteria for healthy and ill persons in each ethnic group
- clear cut description of the translation and evaluation process

### *Optimal*

- as above, but involving a more refined translation process using a number of translation teams and evaluation committees including lay representatives
- use of more comprehensive statistical procedures and psychometric analyses
- establishing general norms for each population, if possible

## **Box 3.2: Recommended minimal and optimal principles of questionnaire adaptation**

However, some researchers do not view the above methodological steps as sufficient to establish true cross-cultural equivalence and see qualitative research as an essential precursor to robust quantitative research in a cross-cultural context (Hunt 1998). It has been recommended that, either when developing a new instrument for use cross-culturally, or modifying an existing instrument, this additional initial qualitative phase is necessary for in-depth investigation into the conceptual understanding of the area under study in each target group. An ideal cross-cultural study should begin with detailed phenomenological descriptions not primarily

designed to test hypotheses (Kleinman 1977); the analysis of this descriptive information should lead to the formulation of a theory explaining cultural differences in a particular area (Eyton & Neuwirth 1984). It is then possible to formulate specific hypotheses which can be tested by quantitative techniques. For example, in relation to pain measurement, some authors have recommended the following stages in establishing cross-cultural pain assessment instruments:

"...it is important in researching [pain description] phenomena to minimize methodologic assumptions and linguistic distinctions borrowed from contexts other than those of the research subjects... instruments designed to assess pain coping were constructed from the descriptions elicited by ... interviews. The interview data thus served as the basis for cross-cultural quantitative indices." (Moore 1990)p. 171, 172

The ideal methodological steps for the production of a cross-culturally valid health status instrument can therefore be summarised as follows:

1. Content analysis of transcripts of in-depth interviews with lay people, by a team of culturally knowledgeable researchers, should lead to the production of a pool of potential questionnaire items. These items should be subsequently screened for acceptability, translatability and appropriateness in each target language/ culture. If an existing instrument is being modified for use in other cultures, these properties should be assessed also.
2. An iterative translation procedure should produce first drafts in each language. Forward and back translation techniques can be used, but within a framework of creative discussion and review. This process should include people monolingual in the target language(s) and should incorporate lay members of each ethnic group. This lay perspective is a crucial part of every stage of the research process (Entwistle et al. 1998). The most complex types of translation process now involve collaborative discussion between





translation teams and the agreement of a 'best fit' after discussion with evaluation committees including monolingual people. Equivalence of response choices should also be established. In multiethnic studies, all language versions should be developed collaboratively to ensure conceptual and functional comparability (Hunt 1998). Items identified as culture-specific can be either revised or replaced with more universally meaningful questions or be placed within core modules.

3. The questions can then be refined through successive phases of reviewing with culturally knowledgeable representatives from each ethnic group. Final versions will have face and content validity due to the above methodological steps.
4. Subsequent to translation, field testing must be carried out simultaneously in each linguistic or ethnic group, in both clinical and non-clinical samples. This process should involve a debriefing procedure when potential subjects discuss their interpretation of the items. Using similar populations, study designs, and measures in different ethnic groups enables comparison of the psychometric properties of the instrument.
5. Following this field testing phase, any items not equally acceptable or responsive in all ethnic groups are removed to ensure strict cross-cultural comparability. However this approach can have considerable disadvantages; some of the items removed may be particularly important or relevant to a certain group or groups, and their omission would lead to the concerns of these groups being under-represented. Additional culture-specific items to supplement core modules can overcome this.



6. If the instrument is not a self-completed measure, the challenge of inter-interviewer bias and intra-interviewer inconsistency should be tackled by providing strict training to ensure uniformity in interviewing. Vigilance in training is particularly important when eliciting information from a range of ethnic minorities, where inter-interviewer bias is compounded by deviations in direction of bias across linguistic groups. Recruiting interviewers from the communities to be sampled and increasing their involvement in the research and analysis process increases the validity and cohesion of cross-cultural work (Kai & Hedges 1999; Nevid & Maria 1999; Small et al. 1999a, 1999b).

The above translation and modification process is an arduous procedure, with rigorous qualitative and quantitative components. However, such a sophisticated approach may not always be necessary. For example, a recent study compared two very different approaches to adaptation of a quality of life measure in France (a 3-month version based on three initial translations, one synthesis and two pre-tests; and a more comprehensive version involving back translations, focus groups, development of cross-culturally equivalent response options, rating the difficulty of translating each item in each language and the quality of the translation, and multiple pre-tests). Results showed both versions demonstrated similar psychometric properties despite extensive wording differences. This finding may indicate that in some cases a moderately resource-intensive translation can produce adequate results (Perneger, Lepke, & Etter 1999). However, the psychometric properties of an instrument can be similar in two different translations for reasons other than the equivalence of the translation. For example, the versions may contain equally

inappropriate or incomprehensible items. In addition, this comparison of methods involved a translation into a single language. When researching multiple languages and ethnic groups, a more discursive translation process may be required to ensure cross-cultural equivalence.

#### ***3.4.4 Methodological implications for the cross-cultural adaptation of the Rose Angina Questionnaire***

Attempts to modify or adapt the RAQ do not have the benefit of any consensual standard methodology. As reviewed in Chapter 2, there are no exemplar studies adapting the RAQ for use in different language or ethnic groups. Moreover, most cross-cultural health measurement has been carried out on questionnaires with psychometrically scalar properties. However, the RAQ is an epidemiological screening tool as opposed to a measurement instrument. The completed questionnaire does not yield a score but the presence or absence of a diagnostic category. It is therefore less appropriate to apply the psychometric validation that applies to other questionnaires. Properties such as internal consistency, scaling assumptions and item-to-scale correlations, used to establish validity, can not apply in the case of a screening questionnaire such the RAQ. As outlined above, it is more important to establish conceptual, lexical and functional equivalence of the RAQ by investigating its face and content validity using qualitative methods.

### **3.5 Cross-cultural health survey research and relevance to the Rose Angina Questionnaire**

A review of cross-cultural literature in the health sciences suggested that face and content validity were rarely considered when modifying or adapting a questionnaire for use in different languages and cultures. Researchers commonly focussed on establishing psychometric (see 3.4.3 & 3.4.4), criterion or clinical validity (see 2.6) of the different language versions without first establishing face and content validity (see 2.7) of the tool. An extensive review of tobacco and alcohol questionnaires in multiethnic national health and lifestyle surveys in the UK revealed a lack of adherence to accepted good practice in cross-cultural methodology, yielding questionnaire items that were both culturally insensitive and linguistically inaccurate for use in non-European populations (Bhopal et al. 2004). As described in Chapter 2, many epidemiological studies using the RAQ in different languages did not specify the translation process, despite many developments in the basic forward/ back translation technique made in other fields. For example, translation specialists propose a detailed evaluation grid in which various language levels are analysed to see whether the translator has matched the goals and structure of the original and achieved functional equivalence with appropriate adaptations for the culture into which the text is being translated (Larose & Fawcett (rev) 1997).

Most translation studies are 'anti-essentialist', meaning they challenge the idea that there is an intrinsically stable meaning in a text or language that is fully transferable to other contexts. The interpretation of a text or questionnaire is shaped by the

translator, the reader, and their cultural context and experiences. It is therefore necessary to be aware of the factors contributing to interpretation and response to a cross-cultural questionnaire and to examine these factors rigorously via qualitative methodology.

### **3.6 Symptom perception and RAQ response: background to cultural differences in symptom perception and relevance to the cross-cultural validity of the RAQ**

It is well-documented that people from different cultures have differing perceptions of illness; for example, cross-cultural variation in symptom reporting of a variety of conditions has been demonstrated (Van den Akker et al. 1995). The variation in epidemiologically-determined prevalence of self-reported diseases between ethnic groups may, therefore, reflect different perceptions of the manifestations of those disease states by different groups.

Ethnomedicine is the discipline which studies how disease states are embedded in a culture and is long established (eds. Currer & Stacey 1986). Kleinman (1980) has described how the cultural meanings of illness and its treatment need to be located within the cultural group itself. He described how 'explanatory models', the beliefs about an episode of illness and its treatment, are culturally specific. The description of a certain experience as 'illness' may not be applicable to people who share a different set of cultural beliefs (Burr 2002).

In cross-cultural survey research, the diagnosis of a disease, such as angina, is based solely on physical symptoms. It has been argued that this approach is ethnocentric because it fails to take into account the cultural factors that contribute to symptom perception and expression; as Good has stated:

"physiological states do not have simple linguistic correlates- disease [is] shaped...by symbolic and social experience" (Good 1977, p.53).

The Rose Angina Questionnaire diagnosis may therefore vary between individuals from different ethnic groups depending on their cultural understanding of the concepts underpinning the questionnaire items.

There are three ways in which symptom reporting in response to a question may vary between ethnic groups. Firstly, an ethnic group may experience and report a symptom differently due to varying cultural norms of symptom perception and/ or expression. Secondly, an ethnic group may respond differently to a question due to a lack of adequate and equivalent translation. Thirdly, there may be cultural factors that affect general response tendencies to questions about health. Hence, the underlying conceptual validity of a health questionnaire needs to be established before a questionnaire can be equivalent in different languages. Conceptual equivalence refers to whether the construct being investigated is salient and relevant to the target population. Lexical equivalence refers to the words in different languages relating to the same subject. As highlighted earlier, there is often a failure to distinguish between the adequacy of a translation on a lexical or semantic level and its adequacy on a conceptual or cultural level. Without this conceptual validity, semantic or lexical validity is meaningless. It is not sufficient merely to ask lay participants whether they understand the RAQ translations. Such a technique would

be superficial, missing underlying conceptual variations in symptom perception and expression, and subject to the obvious types of bias that influence questionnaire response in the first instance: response tendencies such as answering 'yes', social obligation, and lack of task comprehension. A task by which monolingual or lay people were asked to comment solely on the understandability of the words used in the translation into their language would be a decontextualised task, failing to take into account the social network of belief and meaning in which language is embedded. Ideally, therefore, a study should be designed not only to assess the lexical equivalence of different language versions of the Rose Angina Questionnaire, but first to assess the cultural appropriateness of asking questions about angina and chest pain in different communities. In order to assess the conceptual validity of the RAQ in different ethnic/linguistic groups, lay people need to be questioned about a range of health beliefs and behaviour that may have an impact on RAQ response. If conceptual validity exists, the next step must be establishing linguistic, semantic or lexical equivalence. The second component of establishing possible validity, therefore, would be the assessment of the meaning, acceptability and appropriateness of translated RAQ items in the different language groups.

### **3.7 Possible factors affecting symptom perception, self-report and RAQ response**

A number of factors might influence symptom reporting and self-report on the Rose Angina Questionnaire.

### **3.7.1 Pain**

Classical studies on the association between ethnicity and pain proposed that the meaning of a pain and the response to it were culturally learned (Zborowski 1952). Much subsequent work has demonstrated that language and ethnicity are key factors influencing pain expression and that pain has specific cultural significance (Fabrega & Tyma 1976; Flannery, Sos, & McGovern 1981; Koopman, Eisenthal, & Stoeckle 1984; Lipton & Marbach 1984; Pugh 1991; Zola 1966). It has also been shown that ethnicity is a factor in the treatment of pain (Ng et al. 1996; Todd et al. 2000).

Between 1960 and 1996, over 200 academic articles explored the relationship between pain and culture or ethnicity (Ng et al. 1996). Such studies investigated the effect of ethnicity on different types of pain, such as general pain, post-operative pain and laboratory-induced pain. For example, reports that African-Americans show less tolerance to pain than whites have been investigated by comparing thermal pain responses between the two groups (Edwards & Fillingim 1999). It was found that whites and African-Americans differed primarily in the affective component of the pain experience, rather than differing in the sensory processing of pain stimuli. Pain tolerance rather than threshold, and pain unpleasantness rather than severity, were more sensitive indicators of differences between the two groups. There may therefore be linguistic or cultural differences specifically in the affective dimension of pain processing. Other researchers have also suggested that a possible explanation for ethnic group differences in questionnaire pain response may be differences in linguistic interpretation of symptoms and differences in pain vocabulary across languages (Van den Akker et al. 1995).



One author suggests that ethnic differences in pain reporting among migrants could be due to a variety of factors, such as differing pain thresholds, the effect of culture change, or mental health issues (Allison et al. 2002). However, amongst highly-assimilated groups, such as those found in the U.S.A., the ethnic difference in expression of pain persists. Conversely, it has also been reported that the evidence for a relationship between ethnicity and pain is limited (Greenwald 1991). However, in this case the researchers measured pain across different ethnic (unspecified language) groups using two instruments that may be culturally biased, the Graphic Rating Scale and the McGill Pain Questionnaire.

Cultural differences in pain perception may also influence health-care seeking behaviour which may, in turn, affect the report of a doctor's diagnosis of angina, a criterion used to establish validity of RAQ response but which may in itself vary cross-culturally.

### ***3.7.2 Knowledge of heart disease and symptoms of angina and heart attack***

It has been recommended that:

“...insights [can] derive from examining both the nature and meanings of apparently familiar categories- for example, clinical terminology etc...and investigating how and why such categories are constructed and maintained.”  
(Lambert & McKevitt 2002, p.212)

Knowledge about cardiac problems and awareness of the symptoms of angina may vary between ethnic groups and may influence RAQ response. It has been reported that knowledge and understanding of heart disease, its cause and prevention was low



in a South Asian population in the UK (Rankin & Bhopal 2001). In addition, one study has shown that the time from symptom onset to presentation with acute myocardial infarction was significantly longer among South Asian people than a control group (Gupta, Tabas, & Kohn 2002). The authors suggested that possible reasons for the delay in symptom reporting may have included language barriers or decreased awareness of the significance of symptoms. Conversely, another study showed that Bangladeshi patients with acute MI were as likely as white patients to interpret their symptoms as suggestive of MI and to arrive in hospital equally quickly. However, Bangladeshi patients with acute MI more often used non-classical descriptions of their symptoms than white patients, leading to a delay in diagnosis, which may contribute to their longer time from presentation to treatment (Barakat et al. 2003).

### **3.7.3 *Beliefs about chest pain***

Individuals and groups may differ in their perception and construction of clinically distinct categories of thoracic pain. It has been demonstrated that South Asian patients are more likely than white patients to report that they would seek immediate care for the symptoms of angina (Chaturvedi, Rai, & Ben-Shiomo 1997), indicating that the symptoms are perceived as serious. However, it has been shown that some ethnic groups are more likely to interpret chest pain symptoms as gastrointestinal in origin (Klingler et al. 2002). In fact, it has been reported that angina-like chest pain is less likely to be cardiac than oesophageal in origin; for example, in a group reporting Rose Questionnaire angina, more participants had oesophageal disease than coronary heart disease (Tibbling 1981). Even in white (European origin) groups,

researchers have acknowledged that despite chest pain being a common and fundamental symptom of CHD, there has been little research on the quality and nature of chest pain. They conclude that it is

"...important to elicit the patient's beliefs and attitudes about chest pain...further research in the validity of chest pain and other questionnaires is needed" (Chambers & Bass 1998, p.241, 243)

#### **3.7.4 Somatisation/ somatic awareness and concerns about health**

Many studies have described a somatisation process in different ethnic groups in which chest pain, heart pain, or other physical symptoms are expressed as a metaphor for psychological distress, often leading to an underestimate of psychological distress in certain ethnic groups (Angel & Guarnaccia 1989; Fenton & Sadiq-Sangster 1996; Kai & Hedges 1999; Kernicki 1997; Kleinman, Eisenberg, & Good 1978; Kleinman 1977; Krause 1989; Racy 1980; White 1982; Williams et al. 1997; Williams & Hunt 1997).

In white populations, angina and heart disease can be related to depression, emotional stress or anger (Appels 1997; Verthein & Kohler 1997; Williams 1999). However, it has also been reported that culture did not influence prevalence of common mental disorders (Bhui & Bhugra 2001). In this case, however, the 'common mental disorders' were themselves assessed by instruments that may have been culturally biased, thus leading to artefactual response- for example the General Health Questionnaire and the Clinical Interview Schedule. It is possible that in certain ethnic minorities or genders within ethnic groups in which the expression of emotional stress or anger is less acceptable, non-cardiac chest pain may be also expressed as the main manifestation of such distress. Therefore mental state may

significantly affect chest pain experience, symptom perception and subsequent Rose Angina reporting. It has also been shown that anxiety and depression are related to the experience of diagnosed angina- when newly-diagnosed angina patients were randomised between an angina management plan and no intervention, those undergoing the plan to reduce their concerns showed less frequency of attack, less use of anti-anginal medications and less restriction in their physical activity (Lewin et al. 2002). Hence the emotive response to symptom experience can affect indices of anginal severity, and may have a clear impact on responses to standard questions such as those in the RAQ. An individual's concerns about their health may therefore affect their symptom perception and their tendency to self-report.

It has also been shown that in white women, degree of somatic awareness may be an important factor to consider in evaluating response to symptoms of myocardial infarction and to chest pain (Warner 1995). It is possible that there are varying degrees of somatic awareness between linguistic/ cultural/ ethnic groups. Cultural variations in norms of somatic awareness may therefore lead to ethnic variations in symptom perception and subsequent variations in RAQ response independent of underlying pathology.

### **3.7.5 General health experience**

It has been argued that the nature and degree of chest pain symptoms are influenced by psychological constructs such as attitudes regarding life circumstances and beliefs regarding personal or provider control of health and illness, and that chest pain symptom recognition is significantly affected by social circumstances, personal

experiences and knowledge (Linn, Ware, & Greenfield 1980). An individual's general health experience may therefore influence these factors, symptom perception and subsequent RAQ response.

### **3.7.6 Consultation behaviour and attitudes to health care**

It has been shown that socioeconomic status affects an individual's interaction with, and tendency to present to, doctors, in addition to the tendency to normalise or minimise chest pain symptoms rather than bother the doctor (Richards, Reid, & Watt 2002). These factors may vary by cultural or ethnic group in addition to socioeconomic group.

It has been reported that of the 1.8 million people with angina in the UK, the majority is treated medically in primary care (Lewin et al. 2002). RAQ responses may be influenced by a prior diagnosis and treatment of chest pain. An individual's relationship with, and attitude to, the primary care giver may have an impact on diagnosis, knowledge and treatment of chest pain, and may therefore influence RAQ response.

As mentioned earlier, reporting Rose Questionnaire angina has been shown to be more likely amongst blacks in the U.S.A if the participants felt they were not receiving adequate medical care (Smith et al. 1993); similarly, researchers have speculated that the tendency of rural Jamaicans to respond positively to the RAQ in the absence of clinical markers of angina may have been due to a desire to respond appropriately in the hope of being given further medical attention (Ashcroft 1976).

Perceptions of medical need may differentially affect symptom reporting between ethnic groups.

### **3.7.7 Information about health**

Symptom perception is also influenced by knowledge of health, generated within a social context and reinforced by family, friends and colleagues (Moore 1990).

Levels of knowledge about health and sources of information about health may affect questionnaire perception and influence response. Different ethnic groups may report gathering health-related information from different sources.

### **3.7.8 Exercise**

Angina is commonly precipitated by exercise and RAQ items probe the effect of exercise on chest pain symptomatology. Different ethnic groups may have different norms for physical exercise, which may in turn affect likelihood of experiencing chest pain and response to the RAQ. Levels of leisure-time physical inactivity have been shown to influence the development of angina pectoris and myocardial infarction in varying ways. In Western European populations (Northern Ireland and France), increased leisure-time physical activity was correlated with an increase in angina episodes but a decrease in 'hard coronary events' (MI and coronary death) (Wagner et al. 2002). It has been suggested that some angina patients adopt unhelpful coping strategies such as undue rest, and that this may explain the common finding that there is little association between symptoms and physiological indices of cardiac disease (Lewin et al. 2002).

### **3.8 Conclusion concerning cross-cultural adaptation of the RAQ**

Interpretation of RAQ items may vary culturally and linguistically across ethnic group for the reasons outlined in this chapter. The RAQ constitutes a good starting point from which to explore the best way to adapt an epidemiological instrument for valid use in other cultures and languages. Variability in cross-cultural performance has been demonstrated; many issues around cultural variation in symptom perception may affect interpretation of RAQ items; yet it is short enough to be investigated within the context of a Ph.D. project.

## **Chapter 4**

## **Aims and Methods**

#### **4.1 Background to aims**

The assumptions of this study are as follows. As shown in chapter 2, face and content validity of the RAQ in different cultural groups have not been established. It may, therefore, have sub-optimal cross-cultural comparability. Various language versions of the RAQ that have been used in epidemiological surveys have yielded ethnic variations in angina prevalence that may be a function of inadequate translation/ adaptation procedures and which may not reflect underlying differences in CHD across ethnic groups. First, the RAQ may lack conceptual equivalence across cultural groups because of cultural differences in the social construction of health and illness ; also, the meaning and significance of pain and chest pain may affect perception of, and response to, the RAQ questions. Second, existing translations of the RAQ may not be lexically or semantically comparable across language groups. Third, response norms such as tendency to disclosure, familiarity with response categories or an interviewer effect may vary between ethnic groups.

#### **4.2 A note on development of aims**

The original aim of this study was to produce cross-culturally valid versions of the RAQ in various languages. After a review of the literature, it was decided that the volume of work this would involve was beyond the scope of a Ph.D. It was therefore decided to investigate the need for and feasibility of producing such versions. An in-depth interview-based study was chosen to address this aim. Previous translations of the RAQ would be used to examine the appropriateness and equivalence of non-English language versions. Translations by the Newcastle Heart Project (NHP) were selected. NHP researchers were contacted and supplied copies of the Punjabi and



Chinese translations of the RAQ used (see Appendix 2). These NHP translations represent the best practice to date and these met at least some of the criteria for adaptation (as reviewed in chapter 3.4.3). Subsequent work beyond a Ph.D. would be required to establish cross-cultural comparability by using methods such as piloting a modified version on a population sample and testing for validity and reliability.

A second reassessment of the original research plan concerned the intent to carry out a multiethnic validation. National epidemiological surveys investigating cardiovascular variables would require equivalent versions of a questionnaire in many different ethnic and linguistic groups in order to yield comparable results. This selection could include African- Caribbeans; Africans; Indian, Pakistani and Bangladeshi groups (speaking Hindi, Urdu, Punjabi, Bengali, Sylheti and Gujerati); Chinese (speaking Mandarin and Cantonese); and Irish (speaking English). Investigating such a large number of ethnic and linguistic groups is beyond the scope of this Ph.D. project. Multiethnic adaptations and developments of survey instruments are extremely time-consuming. As indicated in Chapter 3.4.3, the adaptations for all ethnic groups should be carried out collaboratively in order to ensure strict cross-cultural comparability. It was therefore necessary to recruit, train and employ additional research staff of appropriate ethnic origin, cultural competence and linguistic skill to carry out interviews and assist with translation and interpretation of interview transcripts. Therefore, for practical reasons, the number of non-English speaking ethnic groups to be studied was reduced at the expense of more comprehensive multiculturalism. The study was limited to 3 linguistic groups.

The three language groups chosen- English, Punjabi and Cantonese- represent the main language of the ethnic majority population and the two biggest ethnic minority groups in Scotland, Pakistani people (speaking Punjabi) and Hong Kong/ Chinese people (speaking Cantonese) respectively. This study, therefore, focused on linguistic groups rather than broadly-defined ethnic groups.

### **4.3 Aims**

#### **Primary aim**

To assess the need for, and feasibility of, modifying the Rose Angina Questionnaire to render it valid for use in Punjabi, Cantonese and English.

A number of secondary aims are subsumed by the overall aim.

#### **Secondary aims**

To investigate whether the RAQ is conceptually equivalent in each of the groups under study:

- To explore concepts of health, illness and health care (including cardiovascular health) and assess ways in which they might affect interpretations of the RAQ questions.
- To explore beliefs about, and the expression of, pain and chest pain.

To investigate whether the RAQ is semantically or lexically equivalent in each of the study groups:

- To assess whether an existing version of the RAQ in Punjabi, Cantonese and English is appropriate, acceptable and relevant to lay people from that

linguistic group, and whether each language version is comparable with each other.

To investigate whether response tendencies affect RAQ outcome:

- To assess whether people from different cultural groups tend to respond to the RAQ questions and the mode of administration in similar ways.

#### **4.4 Development of study design and materials**

The study was initially designed as follows. It was proposed that a sample of approximately 100 people from each of the three linguistic groups, 300 in total, would be selected from one or more general practice registers. The researcher would send a contact pack to the patient. The proposed contact pack documents were as follows (these proposed materials are available on request):

- A letter from the researcher and the general practice informing the participant of the study and of a forthcoming brief screening telephone call;
- A patient information booklet explaining the nature of the study, the confidentiality and anonymity of the telephone calls and the interviews, and the participant's right to withdraw from the project at any time (the patient information was piloted with a small sample of lay English speakers for understandability.)
- A refusal form indicating the patient's unwillingness to be contacted by telephone, which the patient could return to the researcher in a pre-paid envelope if they wished to have no further involvement in the study. Participants who did

not return their refusal form within one to two weeks would then be telephoned by the researcher and asked some preliminary questions.

It was intended that the contact pack documents would be translated into the appropriate language for the ethnic minority participants. The letter would be sent on jointly headed notepaper to indicate collaboration between the University and the general practice. Bilingual project co-workers would be recruited and trained to carry out the telephone calls and subsequent interviews in the participant's language (Punjabi or Cantonese), and the researcher would carry out the telephone calls and interviews in the English-speaking sample. The telephone screening interview form is reproduced in Appendix 3. The telephone screening questions were designed to assess the suitability of the participant for the interview study. On the basis of their responses to the brief (less than 5 minutes) telephone interview, 20 participants from each of the three linguistic groups would be selected for interview. An interview topic guide was developed to address the stated aims of the project (see Chapter 4.11 for interview guide). Selected participants would be asked if they were prepared to participate in a longer interview in their own home, if convenient, and an interview time arranged. The inclusion and exclusion criteria for these two phases of participant contact- telephone screening interview and face-to-face interview- were as follows:

#### Inclusion criteria

1. For telephone contact:

- Age 45 years or over
- 50 men and 50 women for each of three ethnic groups:

- Pakistani (Punjabi speakers)
- Chinese (Cantonese speakers)
- White European-origin (English speakers)

2. For the interview study:

- From each ethnic group:
  - 10 male, 10 female
  - stratified by age (45-54; 55-64; 65-74; 74 and over)
  - 5 of each gender having responded 'yes' to the telephone question "Have you ever had any pain or discomfort in your chest?", 5 of each gender having responded 'no' to the same question
- Preferred language of response: Punjabi in the Pakistani group, Cantonese in the Chinese group.

Exclusion criteria

As indicated above, participants below the age of 45 were not to be contacted. The prevalence of both chest pain and angina is likely to be higher in people above 45 years of age. Additionally, in the ethnic minority samples, people above the age of 45 are more likely to cite the ethnic minority language as their preferred language. These are also the people for whom it is important to have accurately translated and adapted versions of the Rose Angina Questionnaire. Therefore, those people from the ethnic minority groups who indicated that their preferred language of response was not Punjabi or Cantonese were not to be asked to participate. Patients who had already indicated to their GP that they were unwilling to take part in any research

were also excluded, as were any patients identified by their GP as being unfit to take part (for example those with forms of physical or mental illness which would place a strain on the patient or which would complicate the enquiry).

A proposed sample of approximately 20 participants in each of three ethnic/linguistic groups was chosen to represent a mix of genders and ages in each ethnic group. In qualitative research, the interviewing continues until no further pertinent information emerges. On the basis of the experience of the project's academic supervisors and the research literature, 20 interviews in each language were expected to provide sufficient data. The arranged interview was expected to be within a fortnight of telephone contact. Upon arrival, the participant would be asked to sign an interview consent form. Therefore, from initial informative letter to interview, the participant would have up to four weeks to decide whether or not to be interviewed, and three opportunities to decline involvement during that time.

#### Ethical committee commentary

The study proposal as outlined above was submitted to Lothian Research Ethics Committee (Healthy Volunteer Studies/ Public Health Medicine Research Ethics Sub-Committee) and to Lothian Primary Care Trust for ethical approval. (The initial application for ethical approval and the study proposal are available on request). The documents for participants were not translated at this stage but written assurance was given that appropriate translations and translators would be used. Lothian Primary Care Trust approved the proposal subject to the written approval of the Research Ethics Sub-Committee. The Research Ethics Sub-Committee returned comments on

the proposal. (Appendix 4 contains copies of communications from the ethical committee, and responses by the researcher, following application for ethical approval). The main point expressed by the committee concerned patients' confidentiality and the release of patients' details by General Practitioners. They suggested that the initial letter to the patient should be sent, not from the researcher, but from the general practice and signed by the doctor. The letter should state that patients would be telephoned after two weeks, not one week (the proposal had stated 'one to two weeks') and that the refusal letter should be sent to the surgery within those two weeks if patients did not want to be contacted. The committee also recommended that the researcher state that they were telephoning on behalf of the general practice when telephone contact was made. This point, as well as other concerns, was responded to in depth. The researcher argued that it was important that the participant was aware that they were being asked to take part in a research project that was not overly 'medicalised'. Requests were made that the letter could be sent to the patient on jointly headed notepaper and signed by both the GP and the researcher, and that the refusal form could be returned to the University, and not the general practice as recommended by the committee. However, these requests were rejected. The sub-committee had reviewed recently published General Medical Council guidelines that general practitioners should not release information on patients without their consent. The researcher agreed, first, that the contact letter would be sent on GP headed notepaper and signed by the GP alone; and second, that the patient would send their refusal form directly to the general practice. If the patient did not return their refusal form within the designated two weeks, then their GP would release their contact details to the researcher, and the patient would be

contacted by telephone. The researcher suggested that at this stage it was vital to inform the participant that they were being contacted by the University concerning a project being carried out in association with their general practice. This amended protocol was re-submitted. However, the ethical committee responded that, after considerable discussion, it had been agreed that they would grant ethical approval only if the letter to the subjects was reworded so that they

"had to give active consent to be considered for the study. It was agreed that if there were difficulties in recruiting subjects to the study, the sub-committee would be willing to reconsider this issue."

These changes were made.

#### Participant contact packs

Once ethical approval was granted, the participants' contact packs were translated by a professional translation service into Chinese and Urdu, and proof-read for understandability and acceptability by a third person bilingual in English and either Cantonese or Urdu. Whilst Punjabi is the most common spoken language in the home in Pakistani-origin people living in Edinburgh, Urdu is the official, 'public' language of Pakistan and is also the language of literacy. Most literate Pakistanis will be able to read Urdu, but not Punjabi. Final contact packs (see Appendix 5) included English and non-English versions of:

1. A patient information booklet.
2. An introductory letter signed by the GP. This explained the project and requested that the patient give consent for their GP to release their name and telephone number to the researcher for the telephone interview.



3. A consent form to be returned to the practice in a pre-stamped addressed envelope if the patient permitted their doctor to allow the researcher access to their contact details.

#### **4.5 Preliminary community consultation**

Meetings were held with local relevant organisations to generate support for, and advice concerning, the project. The first point of contact was the local Racial Equality Council, which is vital for gaining introductions to community groups and organisations. Other key 'gatekeeping' contacts were the Equalities Unit at the local council and a Minority Ethnic Health Inclusion Project. Subsequently, a number of community ethnic minority groups in Edinburgh were visited (for example the Pakistan Association; APNA, a Pakistani women's group; and a Chinese Elderly Support Association). Once contact was made with such groups, the project was discussed with group leaders to raise its profile and encourage a sense of community participation. An important factor in engendering a positive response to the project, when approaching grass-roots organisations, was the need to employ bilingual members of their communities to assist in carrying out the research. All groups were very helpful in facilitating the advertising for, and the recruitment of, potential bilingual employees, for example by distributing advertisements free of charge in newsletters, mosques and community centres.

#### **4.6 Participant recruitment I: initial GP-based sampling strategy**

The first sampling approach attempted was general practice based. There was good reason to believe that a GP-based sampling strategy would perform well in each of

the three ethnic/ linguistic groups, given the high response rates for participation in health surveys amongst the three ethnic groups under study. Survey response rates from national and local surveys measuring tobacco and alcohol use in various ethnic groups have been extracted by a colleague, Amanda Vettini (AV). (This work was carried out by AV, a research assistant, during a project carried out by our team at Public Health Sciences, University of Edinburgh concerning the measurement of risk factors for cancer in ethnicity and health research; published work by Bhopal et al. 2004). The summarised response rates are shown in Appendix 6. These studies have indicated that response rates in surveys are consistently high, with no clear gap between response rates of ethnic minority participants and that of European-origin participants. It was estimated that by sending out 100 contact packs to each group of potential participants, there would be sufficient response to recruit the required number of volunteers from each of three groups. In addition, a GP-based random sampling technique would ensure that a range of people from various backgrounds and of various ages were given the opportunity to take part, given that the majority (98-99%) of the ethnic minority populations is registered with a general practice.

Five general practices in Edinburgh, thought to have high numbers of ethnic minority participants, were approached to take part in the study. The researcher visited the practices and gave presentations on the project to practice staff. Two practices were not suitable for inclusion due to low numbers of Pakistani and/ or Chinese patients above 45 years of age. All three remaining practices agreed to participate.

However, the general practice-based sampling approach proved difficult. The first challenge was the identification of participants from GP registers. Scotland's ethnic minorities are relatively small compared to those of England, and less densely distributed. Ethnic coding in primary care databases is rare. The general practices approached, despite the fact that they served areas of relatively high ethnic minority density, had little knowledge, either anecdotal or recorded, about the ethnic origin or linguistic needs of their patients. A single practice (practice B) had recently carried out an audit on their Chinese patients and so this group was ethnically coded in the database, facilitating and shortening the sampling process substantially. For the other practices, given the small list size, it was not appropriate to attempt to use a computer-based name identification for possible Chinese or Pakistani patients, although algorithms for identifying South Asian names have been developed and validated in Britain and show good ability to discriminate between different linguistic and religious groups (Nanchahal et al. 2001). Instead, a combination of practice staff's knowledge and the research team's expertise in identifying ethnicity by name was used. The register was manually screened for names of possible Pakistani and Chinese origin by practice staff who could query the likely ethnicity of a surname with the research team if necessary. A name-screening approach has been successfully used in other studies to identify names of a certain ethnicity, both abroad (Gupta et al. 2002) and in Britain (Chaturvedi, Rai, & Ben-Shiomo 1997). To sample the English speaking population, a random sample of 50 men and 50 women was drawn from the European names on a practice register with the inclusion and exclusion criteria outlined in section 4.4. Identified participants were sent the

ethically approved contact packs described above in 4.4 and reproduced in Appendix 5.

#### **4.7 Bilingual project workers**

This research was based upon interviewing lay people in their own language and would require subsequent translation and analysis of the interviews. It was necessary to employ culturally and linguistically skilled project workers and to invest a large amount of time per interview in the translation/ analysis. This process is costly, and extra funding in addition to normal Ph.D. research costs was vital. A small grant of £9,000 from the Scottish Executive's Chief Scientist Office was applied for and awarded to cover these extra costs. The author developed the proposal and costings and prepared the grant application with supervision by Professor Raj Bhopal and Dr. Sonja Hunt; Prof. Bhopal and Dr. Hunt were the named grantholders. (Appendix 7 shows the study proposal submitted to the Chief Scientist Office, referees' comments and the researchers' response. Copies of the grant application and costings are available on request). Funding also covered the translation and production costs of patient information leaflets and participant recruitment.

Posts were advertised widely throughout a range of community newsletters and organisations. (See Appendix 8 for job advertisement). The main tasks of the post were as follows:

1. To carry out a brief telephone screening interview with members of the Chinese and Pakistani communities and arrange a face-to-face interview with participants suitable for inclusion in the project.

2. To carry out interviews in Cantonese or Punjabi with community members about pain and ill health and to ask them about the appropriateness of the RAQ items either in the interviewee's own home or in the University.
3. To assist in the translation and analysis of interviews by discussion with a co-worker, and subsequently with the researcher in English.

The response to the advertisement is shown below in Table 4.1.

	Punjabi speakers	Cantonese speakers
Female applicants	9	8
Male applicants	12	1

**Table 4.1: Response to advertisement for Punjabi/ English and Cantonese/ English bilingual project workers**

Four Cantonese speakers and four Punjabi speakers were shortlisted and interviewed. The qualities of the project workers being vital to the research, the following table shows the selection criteria for the post (the selection criteria were modified after those kindly supplied by Dr. Judith Bush from the University of Newcastle and her colleagues Dr. Joe Kai and Dr. Martin White).

**Table 4.2: Person Specification/Selection Criteria for the post of project workers for a qualitative study of pain and ill-health in Punjabi and Cantonese men and women**

Criteria	Essential (please do not apply unless you have these skills)	Desirable (please feel free to apply if you do not have these skills)	Means of Assessment
Education, qualifications and training	<ul style="list-style-type: none"> <li>None</li> </ul>	<ul style="list-style-type: none"> <li>Qualification in interpretation or translation</li> <li>Qualification in community or qualitative research</li> </ul>	<ul style="list-style-type: none"> <li>CV, interview &amp; references</li> </ul>
Experience	<ul style="list-style-type: none"> <li>Familiarity with Punjabi-speaking or Cantonese-speaking communities</li> </ul>	<ul style="list-style-type: none"> <li>Experience of talking to people in a professional capacity</li> <li>Experience of research interviewing</li> </ul>	<ul style="list-style-type: none"> <li>CV, interview &amp; references</li> </ul>
Skills	<ul style="list-style-type: none"> <li>Excellent verbal communication</li> <li>Fluency in English</li> <li>Fluency in either Punjabi or Cantonese</li> <li>Ability to translate orally from Punjabi or Cantonese into English and vice versa</li> </ul>	<ul style="list-style-type: none"> <li>Good written communication</li> <li>Ability to read and write Punjabi/Urdu or Cantonese</li> </ul>	<ul style="list-style-type: none"> <li>Interview and language test</li> </ul>
Personal qualities	<ul style="list-style-type: none"> <li>An ability to work closely with people from different cultural backgrounds</li> <li>Ability to work both independently and as a member of a team</li> <li>Respect for privacy and confidentiality</li> <li>Able to work flexible hours</li> <li>Well organised</li> </ul>	<ul style="list-style-type: none"> <li>Self motivation</li> <li>Ability to work well with regular supervision</li> </ul>	<ul style="list-style-type: none"> <li>CV, interview &amp; references</li> </ul>

Previous cross-cultural work has emphasised the necessity for tests of language and interpretation proficiency before appointing staff to this type of post (Small et al. 1999; Judith Bush, personal communication). A local 'Community-Based English as a Second Language' organisation was contracted to develop an appropriate test of language proficiency that could be administered by their staff to the shortlisted applicants at interview. A mock interview was recorded in Punjabi or Cantonese, in which the actor gave information about a present, past and childhood health problem and described the type, location and duration of pain during the incident. Applicants were asked to listen to this pre-recorded interview and to complete a table indicating the relevant information they were to translate. They were then asked to give an oral summary of the role-play in English to the examiner, using the information they had noted down. The examiner then graded the candidate's performance in each of four translation skills: completeness, accuracy and appropriateness, vocabulary and syntax, and terminology (see Appendix 9 for the language test documents). Written skills in Punjabi/ Cantonese and English were not tested, as they were not necessary for the job.

Two Cantonese and two Punjabi speaking project workers were appointed with the requisite skills and potential to carry out responsive interviews and then provide a discursive translation and analytic commentary to the researcher in English. The project workers appointed to carry out the Cantonese interviews were both female (CC and JL). As initial consultation work had suggested that it would be more appropriate to gender-match the project worker with participants in the Pakistani



Punjabi speaking community, both a male and a female Punjabi speaking project worker were appointed (MA and MK). Shortly after the interview study began, MK, the female project worker, resigned from the post and a previously shortlisted female project worker, JK, replaced her. The project workers were employed on an *ad-hoc* basis, i.e. they were not contracted, salaried staff. During training and translation sessions, bilingual project workers were paid £12 per hour for their work. This was slightly more than the hourly rate paid at the time of field work by the City of Edinburgh Council's Interpreting and Translating Service to its sessional interpreters. A flat rate of £17 per interview included travel and interview organisation costs.

Project workers had little or no prior research experience and an intensive training programme was developed to provide:

1. a thorough grounding in the background and aims of the project
2. interviewing skills and practice
3. discussion of the interview topic guide
4. an introduction to qualitative analysis
5. discussion of practical, safety and ethical issues.

The project workers took part in three training sessions, each lasting three and a half hours. They were given a comprehensive training pack for reference, including all relevant theory and background information, study documents and task checklists (See Appendix 10 for training pack, excluding the interview topic guide which is reproduced below). Some training pack materials drew heavily on those provided by Dr. Judith Bush from the University of Newcastle who, in collaboration with Dr. Joe



Kai, had organised a comprehensive 8-week training programme for community researchers on a qualitative project exploring smoking behaviour in Pakistani and Bangladeshi adults in Newcastle (Bush et al. 2003; White et al. 2002).

Session 1: Project workers were asked to discuss with the researcher their expectations of the job and the training process, their strengths and weaknesses and the areas in which they anticipated they would require the most help. Subsequent training sessions were responsive to any concerns raised by the project workers. The training session then proceeded to cover the background to the project. The researcher presented and discussed the research proposal as submitted for funding, including academic rationale, aims, research questions, sampling strategies, literature review and references. Ethnicity, health, coronary heart disease and the project workers' own experiences of the communities were discussed.

Session 2: A description was given of different participant sampling strategies and the proposed method of sampling for this project. Interviewing skills and good research practice, including participants' rights and the principle of informed consent, were explained and discussed. A code of conduct for interviews was distributed. The Rose Angina Questionnaire in Chinese and Punjabi (see Appendix 2) was presented together with the interview schedule. These were discussed at length. It became clear that neither of the Pakistani Punjabi-speakers were able to read the Punjabi script, and therefore could not read the Punjabi version of the RAQ. Pakistani people may be more likely to be literate in Urdu than Punjabi. It was therefore necessary for the researcher to ask another Punjabi speaker who was

literate in Punjabi, from a local community organisation, to read the questions aloud into a tape recorder. Copies of this tape were then given to the Punjabi-speaking project workers in order that they could hear the Punjabi version of the RAQ and use the same wording in the RAQ assessment exercise with participants. The Cantonese project workers were able to read the Chinese script and were given a paper copy of the RAQ. The three language versions of the RAQ used included, in the same section, a single screening question for myocardial infarction: "Have you ever had a severe pain across the front of your chest lasting for half an hour or more?" It was decided to include this additional question in the lay assessment task.

Project workers listened to tapes of the researcher carrying out interviews to illustrate good (and bad) practice. Project workers carried out mock interviews with each other and any issues, problems or questions raised by the process were discussed and resolved.

Session 3: The principles of qualitative analysis were discussed and the translation process explored. The project workers were reminded of the project's research questions and of the information they should pay attention to whilst translating and helping to analyse their interviews. The participatory, reflexive nature of their role was emphasised, and it was stressed to them that their cultural insight was vital in illuminating participant's perceptions and providing a 'bridge' between the participant's voice and the perspective of the white English-speaking researcher. The practicalities of the job, including health and safety issues pertinent to lone working, were addressed. Despite offering to provide all the project workers with personal

alarms and a phone-in system to ensure safe completion of interviews, only one project worker wished to have the personal alarm and the phone-in system rapidly dwindled in use. The project workers did not feel under any threat when carrying out interviews within their own community. To comply with the Data Protection Act, project workers signed an Oath of Confidentiality (Shown in Appendix 11). Project workers were given University Staff ID cards, tape recorders, tapes, batteries, participants' consent forms, telephone interview forms, and field notes forms. They were provided with a hierarchy of contact telephone numbers (the researcher, the team secretary, the project supervisor, and their co-workers) in case of queries or emergencies.

#### **4.8 Low response rates**

Despite the resource- and time-intensive preparation described in sections 4.4 and 4.6, the GP-sampling approach failed to recruit sufficient participants from the Pakistani and Chinese groups. The response rates are shown in the following table.

**Table 4.3: GP-based sampling responses in 3 linguistic/ethnic groups in Edinburgh**

<b>General Practice</b>	<b>Number of contact packs posted</b>	<b>Number of responses (percentage)</b>
<b>A</b>	100 English	39 (39%)
<b>A</b>	31 Cantonese/ English	5 (16%)
<b>B</b>	31 Urdu/ English	4 (13%)
<b>C</b>	90 Cantonese/ English	5 (6%)
<b>C</b>	42 Urdu/ English	4 (10%)

As can be seen, the response rate for English speakers was higher (39%) than the response rates for either potential Cantonese-speaking participants (average 12%) or Punjabi-speaking participants (average 12%). Overall, using this type of written contact from the GP and depending on the participant reading, signing and returning a consent form to their GP, only 8 Pakistani Punjabi speakers were recruited from 73 approached and 10 Chinese Cantonese speakers from 121 approached.

#### **4.9 Participant recruitment II: community based and snowball sampling strategy**

To recruit sufficient Pakistani and Chinese participants, the original GP-sampling strategy was supplemented with community-based sampling via community organisations, project worker contacts and snowball sampling. Before doing so,

however, the researcher reported back to the ethical committee and requested ethical approval for a community-based sampling approach, which was granted after some time (See Section 4.13 for the ethical approval timeline). Working closely with the bilingual project workers, the researcher attended a Chinese community lunch club and women's group to recruit participants. Pakistani community groups were attended by the Punjabi project workers and participants recruited. Community group leaders were approached and asked to provide contact with people eligible to take part. Other participants were recruited via project workers' personal and community contacts, and by asking interviewees if they knew of anyone who would be willing to be contacted and screened for taking part. In the next section, table 4.6 shows the eventual distribution of sources of recruitment of those interviewed.

#### **4.10 Characteristics of the sample**

In-depth, semi-structured interviews were carried out with a broad age range of men and women above the age of 45 from the Punjabi, Cantonese and English-speaking communities in Edinburgh. Tables 4.4 & 4.5 show characteristics of the female and male participants from each group. It proved possible to carry out more interviews than originally planned. The final number of people interviewed in each group was 15 men and 14 women from the Cantonese-speaking community, interviewed by CC and JL; 13 men and 13 women from the Punjabi-speaking community interviewed by MA, MK and JK; and 12 men and 13 women who spoke English as a first language who were interviewed by LH. Table 4.6 shows the distribution of sources of recruitment for the interview study.

**Table 4.4: Characteristics of female participants interviewed**

	English speakers		Pakistani Punjabi speakers		Cantonese speakers	
Age range	Chest pain?		Chest pain?		Chest pain?	
	<i>Yes</i>	<i>No</i>	<i>Yes</i>	<i>No</i>	<i>Yes</i>	<i>No</i>
<i>45-54</i>	4	1	2	2	1	3
<i>55-64</i>	---	2	5	1	3	1
<i>65-74</i>	2	2	2	---	2	1
<i>75 &amp; over</i>	---	2	---	1	2	1
<b>TOTAL</b>	6	7	9	4	8	6

**Table 4.5: Characteristics of male participants interviewed**

	English speakers		Pakistani Punjabi speakers		Cantonese speakers	
Age range	Chest pain?		Chest pain?		Chest pain?	
	<i>Yes</i>	<i>No</i>	<i>Yes</i>	<i>No</i>	<i>Yes</i>	<i>No</i>
<i>45-54</i>	2	2	2	3	3	1
<i>55-64</i>	1	1	3	2	---	1
<i>65-74</i>	2	1	---	2	3	4
<i>75 &amp; over</i>	2	1	1	1	1	2
<b>TOTAL</b>	7	5	6	8	7	8

**Table 4.6: Numbers of participants interviewed from each source of recruitment**

Source	English speakers		Pakistani Punjabi speakers		Cantonese speakers	
	Women	Men	Women	Men	Women	Men
General Practice	13	12	2	4	2	5
Community groups/ community leaders	---	---	4	3	6	5
Project worker contact	---	---	6	6	5	5
Snowball effect from other participants	---	---	1	---	1	---
<b>TOTAL</b>	<b>13</b>	<b>12</b>	<b>13</b>	<b>13</b>	<b>14</b>	<b>15</b>

#### **4.11 Interviews- location and content**

An initial telephone screening interview was carried out prior to interview based on the form mentioned above in section 4.4 and shown in Appendix 3. If the participant was suitable for inclusion in the study according to the inclusion criteria outlined above, and agreed to participate in a further interview, a pre-interview details form (Appendix 12) was filled in by the researcher or project workers. Interviews were carried out in a location acceptable to participants-usually their own homes, but in a

very small minority of cases the participants chose to be interviewed in the University, and in one instance the project worker's home. Participants signed a consent form prior to interview (see Appendix 13) and gave permission for all interviews to be taped. Project workers completed an interview field notes form before and after the interview (see Appendix 14).

Interviews were designed to assess the following:

Conceptual appropriateness of the RAQ: In order to assess the cultural construction of health and illness in which chest pain beliefs and question responses are embedded, health beliefs and experience from each of the above three different language groups were investigated. Participants were asked to describe their understanding and experience of pain and ill health, their health concerns, their beliefs about influences on health, and their understanding of angina and heart disease.

Lay assessment of translations: In order to assess the linguistic validity of previous translations of the Rose Angina Questionnaire, participants were asked to comment on the understandability and appropriateness of RAQ items in their language.

Cultural factors influencing questionnaire response tendencies: To assess whether there may be a cultural component in response tendencies to questionnaires and health research, participants were asked about their attitudes to questionnaires, their reasons for taking part in research their opinions and experiences of health care.



Box 4.1 shows the topic guide as originally presented to the project workers. As discussed in 8.2.2.3 and 8.2.2.4, project workers differed in the way they carried out the interviews, and the guide was followed to varying degrees.

---

## INTERVIEW TOPIC GUIDE AND QUESTIONS

*Project workers: please note the following is a flexible topic guide only. It is not a questionnaire to be read out to the participant! These questions will be asked in different sequences depending on the individual's responses. This is an example of some of the questions to cover, but you must tailor your interview to fit the individual and the time available. Core questions relating immediately to the research aims are in bold. Topic guides may also change over the course of the project depending on the analysis and responses.*

- **Greetings, thank you and introduction**

E.g. Thank you so much again for agreeing to speak to me today. What we're interested in is hearing your opinions and your experiences of pain and ill health in your own words, so please feel free to speak honestly. May I begin by asking you:

- **General health-related beliefs/ experience of pain**

How would you describe your health? *Probe- now and throughout your life?*

Have you experienced much pain throughout your life? What kind of pain? Can you describe it? How would you describe your pain threshold/ tolerance?

Do you have any concerns about your health? *Follow up- why? Particularly if there is family history of heart disease- probe further and feed into heart disease questions*

Do you think you consult your doctor more or less than other people your age?

You mentioned you go to the doctor [how often]. What do you think of the care you have received from doctors in the past?

What is your attitude to medication?

- **Follow-up of telephone questions**

*(If necessary, probe using answers to telephone yes/ no interview relating to indigestion, pain when taking exercise, pain/ discomfort in chest) e.g.*

You said on the phone that you'd had indigestion- could you tell me a bit about that? How would you describe the pain? *If answered yes to pain and discomfort in chest, probe then lead into heart disease questions*

You mentioned you had/had not ever had any pain when taking exercise. Can you tell me a bit about that? How would you describe your fitness?

Whenever I asked you on the phone whether you had ever had any pain or discomfort in your chest, you said...

(If yes)...could you tell me a bit about that? What do you think caused it?

What do you think I was asking you about when I asked you that question?

Would you say there was any difference between a pain and a discomfort? How would you describe the difference?

Can I ask you to describe or show me where you are referring to when you use the term "chest"? *Probe if participant female and not mentioned it herself- If I asked you about your chest would you ever think I was referring to your bust or breasts?*

- **Lay assessment of Rose Angina Questionnaire translations**

Thanks for sharing so much with me. I'd like to move on to the second part of the interview now and get your opinions on this list of questions. Can I ask you the following list of questions and can you tell me if they make sense to you or if you think they are confusing? *-Read through RAQ questions. For each question probe:*

- What do you think of this question?
- Can you think of a better way to ask this question?
- *Also probe the meaning of each word/ phrase in more depth*

*Final question "Have you ever had a severe pain across the front of your chest lasting for half an hour or more"- ask What do you think I am asking you about when I ask you that question?*

- **General views/ beliefs/ sources of information/ motivation**

**Could you tell me what the term "angina" means to you? *Reassure the participant: There are no right or wrong answers, we are interested in what you think. Probe: do you know what angina feels like? How do you know this?***

What do you think causes heart disease?

What type of things do you think can influence someone's health?

Where do you think you get your information about health and illness? (*Probe if necessary if participant unresponsive- for example, some people get information from their doctor, or from health promotion campaigns, or from the TV, or from magazines or newspapers, or from family and friends.... do you think any of these sources of information, or any others, apply to you?*)

Have you ever been asked to fill out a questionnaire about your health? About anything else? What is your attitude to questionnaires or surveys that come through the post?

Do you mind if I can ask you why you were so kind as to return your details to the surgery to allow us to contact you?

*Ask participant always to explain words/ phrases they use...e.g. What do you mean by heart problems? What do you mean by...? Could you tell me a bit about that? How would you describe that?*

---

#### **Box 4.1: Interview topic guide**

#### **4.12 Data preparation, coding and analysis**

All data were anonymised on paper, tape labels and computer files. Names were not mentioned on the interview tape and, in the case of non-English interviews, the taped translation process (described later in this section). Participants were assigned a code, consisting of a number and letters to indicate their gender (M or F) and language (P, C or E for Punjabi, Cantonese and English respectively). Participants' names were replaced by these codes on all written data and computer documents. Consent forms containing the participants' names and their codes were kept in a locked filing cabinet.

In the case of the interviews carried out by LH with European-origin English speakers, interview tapes were transcribed verbatim by either LH or a secretary. If transcribed by a secretary, LH listened to the tapes again whilst reading the transcript and made modifications to the transcript where appropriate, based on recall and familiarity with the interviewee, in order to increase the veracity of the transcription. These transcribed English data were then ready for subsequent manipulation and analysis.

In the case of interviews carried out in Punjabi or Cantonese by a bilingual project worker, the process of producing hard copies of the data and preparing them for analysis was less traditional and more complicated. Given that the research was focussing on both the cultural and, importantly, the linguistic appropriateness of the RAQ in Punjabi and Cantonese-speaking communities, it was vital to be able to discuss, with the interviewer, the participants' choice of words in their own language and the cultural meaning or context of any utterance. This was particularly the case when translating the RAQ assessment exercise, which depended on explanation of particular RAQ items, words and phrases in Punjabi and Cantonese and required knowledge of the non-English terms used in order to capture the subtleties and nuances of expression and interpretation in these languages. Hence the option of having the interview tapes translated and transcribed into English by an independent professional, prior to traditional qualitative analysis, was not appropriate. This approach would have included the subjectivity and possible distortion of lay people's

speech that is a possibility when professional bilinguals translate a text (as described in Chapter 3).

Therefore, the process of data analysis, for the Punjabi and Cantonese data, did not start with full interview transcripts. Instead, an innovative and labour-intensive method was used to maximise robustness of the translation/ interpretation process, and include the cultural knowledge necessary for the English-speaking researcher to interpret and analyse the data sensitively. For each interview tape, a 3 to 5 hour process took place that encompassed interview translation, cultural commentary and preliminary descriptive categorization of data. Three people were present throughout this process: the researcher, the interviewer who had carried out the interview in either Punjabi or Cantonese, and the remaining project worker who was fluent in the language of the interview. The decision to include both project workers was made to increase the validity of the translation process and avoid subjectivity or bias arising from a single translator. The presence of two translators meant that a collaborative translation could be made and, where items for translation were ambiguous, a consensus or understanding could be reached by discussion between the project workers and in response to the researcher's queries. As will be shown later in the results (6.2.4), the presence of a second translator giving their opinion or interacting with the project worker who had carried out the interview also meant that the researcher, by observation of their interaction and direct querying of agreement by the second translator, was able to monitor an interviewer's performance and grasp the subtleties of language use more easily than would have been possible if a single perspective had been presented.

Therefore, the researcher, the interviewer and the second project worker fluent in the particular language met round a table and listened to the taped interview.

Usually one project worker would take the lead on translating the interview tape verbally to the researcher. This worker would play the interview tape, and stop after each few sentences to translate the questions they had asked during the interview or the participants' responses and utterances. After each short section was translated verbally, the researcher would ask the second project worker if they agreed with the translation or whether they had anything to add; once the project workers were comfortable with the process, this information was offered more spontaneously and a free and open dialogue took place between the two project workers and between the project workers and the researcher. Throughout this process of interview translation, the researcher was then able to probe more deeply the exact words used in Punjabi and Cantonese during particular utterances and to query certain cultural constructs with the project workers, who were able to provide information on the norms and practices within their community. As aforementioned, throughout the translation of the RAQ assessment task, it was particularly important to note certain words in Punjabi or Cantonese and to have the participants' responses explained and contextualised. For example, in instances where the participant was silent or gestured a response rather than vocalising an answer, the interviewer was able to relay to the researcher what meaningful action had taken place. Similarly, where a participant's verbalised response was ambiguous, the interviewer was able to assess the intended meaning of the response based on their knowledge of the participant and the interview context.

This process of interview tape playing, translation, discussion and questioning by the researcher was also tape-recorded for information. It was not possible, however, to transcribe these sessions; as each session lasted 3 to 5 hours and 60 sessions took place, the time required to transcribe the data arising would have been prohibitive for the researcher. In addition, it was not possible for a secretary to transcribe the tapes, as some knowledge of Punjabi or Cantonese was necessary when particular words in these languages had been noted throughout the discussion. Instead, data arising from these sessions was recorded on a form developed by the researcher (See Appendix 15 for shortened form). In this way, the researcher was able to make notes of participants' responses under certain categorized headings- as shown in Appendix 15, these headings corresponded approximately with the main interview topics as presented in the topic guide in the previous section, including assessment of each RAQ item. The researcher would record the participants' responses in English, using the best translation agreed upon by the two project workers, and where appropriate would annotate the notes to indicate the use of an English word by the participant or the particular Punjabi or Cantonese word used by the participant when speaking about a concept relevant to the study, such as angina, chest, heart, heart disease, pain, discomfort, illness, and other words used to describe symptoms.

After this preliminary translation, descriptive analysis and cultural commentary, the data extracted into extensive handwritten note form were typed into a computer document and analysed further by LH alongside the full interview transcripts from the English-speaking interviews. A word processing program was used for storage



and retrieval of data; qualitative analysis software had been investigated but it had been decided that the sophistication of qualitative analysis software was unnecessary, due to the nature of the enquiry and the form of the non-English data which was, in the process of recording, grouped into initial descriptive categories. English transcript data were coded and grouped into similar initial descriptive categories to the Punjabi and Cantonese data. For each age and gender group, relevant quotes from participants were manually collated for each of the above topics, and content and thematic analysis carried out by re-reading, comparison of data across and between groups and searching for deviant cases. Emergent issues were coded into dominant categories and unifying themes in an iterative process. Firstly, the data were examined to investigate whether there was reason to believe that health and illness, including cardiovascular health, were constructed so as to impact upon the validity of the RAQ. Secondly, participants' comments on the relevant version of the Rose Angina Questionnaire were assessed. Items that suggested modifications of the existing versions of the RAQ were pooled. Thirdly, the data were examined for general questionnaire response tendencies that might influence RAQ response

#### **4.13 Timeline of study and ethical approval**

The stages outlined above are presented in approximate chronological order, but there was a large degree of overlap between the phases outlined. Appendix 16 demonstrates the evolution of the project and the duration of overlapping phases of key stages in the study's preparation and fieldwork. Box 4.2 illustrates the time spent throughout the process of gaining local authority ethical approval for the study.



<b>Ethical approval</b>	
16 <sup>th</sup> August 2000	Application for ethical approval submitted
1 <sup>st</sup> September 2000	Application considered at sub-committee meeting
7 <sup>th</sup> September 2000	Management approval granted from primary care trust subject to ethical approval
20 <sup>th</sup> September 2000	Sub-committee returned comments
27 <sup>th</sup> October 2000	Comments responded to
13 <sup>th</sup> November 2000	Sub-committee returned further comments; comments responded to, agreeing to comply
December 2000	Ethical approval granted
April 2001	Following discussion with supervisors and piloting, participant documents amended slightly for clarity and ease of translation
19 <sup>th</sup> April 2001	Amended documents submitted to ethics committee
15 <sup>th</sup> May 2001	Ethical approval granted to use amended documents
22 <sup>nd</sup> May 2001	Amended document submitted for primary care trust approval
17 <sup>th</sup> August 2001	Following failure of GP sampling strategy, LH spoke to the ethics committee chairperson to discuss alternatives; chairperson insisted on written application
27 <sup>th</sup> August 2001	Submitted request to ethical committee for approval to a) contact participants from GP register without patient's active consent; b) community-based sampling
7 <sup>th</sup> September 2001	Ethical committee meeting
1 <sup>st</sup> October 2001	Ethical committee granted approval for community based sampling strategy or for "practice's regular interpreter" to call patients

**Box 4.2: Timeline for gaining ethical approval of the study**

## **Chapter 5**

### **Cultural appropriateness of the concepts underlying the Rose Angina Questionnaire**

## 5.1 Introduction

Before investigating the linguistic acceptability and equivalence of the Rose Angina Questionnaire, the underlying conceptual appropriateness of the questionnaire in each culture must be established. This study assessed the feasibility of asking questions about angina in three different cultures, by gauging the degree of concordance between the assumptions inherent in the Rose Angina Questionnaire and the health-related world-view of the cultures in which the questionnaire is being administered. This study therefore sought to establish how the concepts of health and ill-health, angina/ coronary heart disease, and pain were constructed within each culture and language.

This chapter is divided into four further sections. Section 5.2 describes general health beliefs, attitudes and behaviour. Section 5.3 addresses knowledge and awareness of cardiovascular health, heart disease and angina. Section 5.4 examines beliefs about pain. In these sections, the themes emerging from the interviews in three language/ cultural groups are reported. If a theme was dominant in a particular cultural group, this is stated in the text; if a theme was present across all groups, illustrative quotes are presented that are representative of some participants from all language and cultural groups. Section 5.5 concludes by summarising the findings in relation to the underlying concepts embedded in the Rose Angina Questionnaire.

### A note on presentation of quotations

Word in quotation marks: a non-English speaker has used an English word

Word in italics: Punjabi or Cantonese word

Word in (...): translation of previous word or phrase

Words in [...]: comment by a project worker or researcher

Participant labels:

M= male

F= female

Number = participant identification number

P= Punjabi-speaker

C= Cantonese speaker

E= English speaker

e.g. 45-54= age group

## **5.2 Results: General health issues**

In order to ascertain whether there were any cultural factors relating to general health that might influence response to the RAQ, participants' experience of health and illness, their beliefs about factors influencing health, their concerns about health, and their sources of health-related information were investigated.

### **5.2.1 Self-reported health and health experience**

Participants of all ages and ethnicities and both sexes reported a wide range of general health problems and illnesses. Some participants reported no health problems and reported their health as being very good or excellent:

"From childhood up to now I have had wonderful health. I have never ever had any major illness." (M2P, 45-54)

Other participants assessed their health as good and said they had not experienced much illness or only minor complaints such as colds:

"My health is generally very good and I even have few headaches and colds, less than once a year." (M14C, 45-54)

"I would say fairly good. I don't have any serious health issues at all...I think I pick up colds and flus and things like that about the same as the average person but I'm not prone to any condition." (F12E, 45-54)

In addition, people sometimes described their health in very positive terms overall despite having chronic health problems:

"Overall, very good, no problem." (M1C, 45-54) [diabetes]

"Good." (F15E, 75 or over) [two or three strokes]

However, other participants assessed their health as not too good:

"At the moment my health is not particularly good." (F14C, 55-64)

"It wasn't too bad but after my 'heart bypass' in 1997 I had pneumonia...I was in hospital for 3 weeks. I catch infections quickly. My resistance is low. So the doctor has told me to be extra vigilant concerning my health." (F16P, 55-64)

Others reported their health as being bad, sometimes citing their current health problems as evidence:

"I am not very well; I have trouble everywhere, trapping me." (F3C, 65-74)

"My health is damaged. I'm 'no well'. I am not well (*teek*) for the past 5-6 years. My head is bad. I had 'gas' in my stomach." (M9P, 55-64)

Whilst the majority of English-speakers described their subjective health experience as good or quite good, a minority described it as bad:

"At the present moment it's poor." (M11E, 75 or over) [polymyalgia rheumatica, heart failure]

Some English-speaking participants were positive about their health, particularly in view of their age:

"Well, having reached the age of 94, I cannae say I've had much- I mean it's a sign of pretty good health." (M13E, 75 or over) [prostrate, mobility problems, angina]

"I would have said I've had very good health, I think, you know, when you reach your threescore years and ten you count yourself as very lucky that, you know, you haven't had anything much terribly wrong with you." (F4E, 65-74) [lower back pain, underactive thyroid]

"Well, I feel at my age I've got wonderful health." (F6E, 65-74) [tiredness, suspected heart problem, asthma, bronchitis]

A couple of Cantonese participants spoke about negative effect of increasing age on their health:

"Not very well. It's old age- I'm 'ill' every 3-4 days." (M3C, 75 or over)

"My health has deteriorated since the menopause- it was very good before that." (F4C, 45-54)

In a small number of interviews, participants were asked what the term health meant to them. A couple of participants articulated that health had a duality (physical and mental):

"I can separate it into two things- physical health (*yuk thai gin hong*) and mental health (*tsing tsang*). Physical health means no illnesses. Whether you're fat or thin doesn't matter, these are not signs of health. Mental health means not depressed. With energy, full of life." (M8C, 45-54)

"A sense of well-being... both [physical and psychological]." (M7E, 55-64)

Others expressed health in very functional terms, as being able to carry out everyday activities without assistance:

"At my age that I can walk, I can eat, I can run, I can do everyday things, I don't need anyone to help me. So I feel lucky compared to other people my age." (M13C, 75 or over)

"I suppose being able to do whatever you want to do, really. Not to be restricted by an ailment from doing what you want to do." (F12E, 45-54)

"No illness. Can eat, can sleep, don't need medication, that's health." (F6C, 55-64)

### **5.2.2 Influences on health**

When asked what type of factors influence an individual's general health, participants from all groups mentioned lifestyle factors such as diet, exercise, stress, smoking and drinking to excess. For example, diet was seen by participants from all ethnic groups to be one of the most important factors influencing an individual's health.

"Health arises from the food you eat. The most important thing is food, if the food is poisonous. You get illnesses through something you eat or drink. Disease is got through your mouth [Chinese saying]." (M3C, 75 or over)

"Eat well." (M13P, 45-54)

Participants from all groups held similar opinions as to what constituted a healthy diet- one rich in vegetables, fruit and fish, and low in non-lean meat, fat and fried foods:

"Don't eat fried foods. Don't eat fat. Eat more vegetables, bean curd, use less seasoning, have more lean meat." (F14C, 55-64)

"For *hartack* (heart attack) people say don't eat certain things, eat less, don't eat *thinda* (greasy foods), don't eat fatty meats, eat less fat and butter, eat boiled vegetables. I eat a lot of fish- it doesn't give you *takleef* (ill-health), it keeps you slim and it is very good for your 'health'." (M8P, 55-64)

"We eat quite healthily, we eat a lot of vegetables and salads and fruit and don't eat red meat, we eat chicken, fish- we don't eat a lot of processed foods, or junk food or anything like that. That's probably the main thing I do to look after my health." (F5E, 45-54)

Regularity and restraint in eating was also seen as important:

"Meals at regular times. I have 3 meals a day and don't snack." (F4C, 45-54)

"Don't eat too much, eat on time." (M10P, 55-64)

A few Cantonese participants thought that healthy food should not be over-seasoned:

"If you eat things that are too sweet, salty or spicy it's not good." (M13C, 75 or over)

In the Cantonese group, there was a conceptual division of foods into hot, moderate and cold foods, referring to innate properties of the foodstuff and not the temperature of the food.

"The type of food and the cooking method affects health as well. You shouldn't eat all cold or all hot food. Steaming, poaching, boiling, these are all moderate methods. Some foods are cold (*choi sum*) in nature and some are moderate (*pak choi*). When a mother has not a balanced diet [balanced in terms of the proportions of hot, moderate and cold foods eaten], it affects the child's health. When you eat cold food you get itchiness in throat, coughing. Try to eat a balanced diet- if you eat only moderate food, the hot/ cold food will be more prominent." (F4C, 45-54)

"Some types of vegetable are not good, like aubergine. It's *sup it* (hot and wind)." (F16C, 75 or over)

"Food. Some food is cold- for example watermelon leads to serious coughing during the night. Some people can take cold food, some hot, so you can choose what type you are and take foods suitable for you." (M4C, 65-74)

A couple of participants mentioned the property *duk*- literally translated as poisonous, but used to refer to foods that have a property that is detrimental to an individual's health:

"*Duk* stuff is not good for you, like roast duck." (F12C, 65-74)

"If you don't have illness you can eat anything, but if you're not well you have to watch what you eat, *sup it* [hot and wet properties]. Prawns and crabs, shellfish, and don't eat the *duk* stuff. If someone has an operation never eat bamboo shoots- even if it was 10, 20 years ago don't eat it because the wound will open. A neighbour had breast cancer, which was cured and one Chinese New Year she bought and ate bamboo shoots and she died two days later. Carp is also very *duk*." (F16C, 75 or over)



"[Because of my operation] I was told not to eat sour things, spicy things, *duk* things. Myself and my husband are both anaemic, so we take cherry tomatoes and kiwis, but then later people told me that they were sour things and not good for my wound." (F12C, 65-74)

Another participant, whilst not mentioning the properties of food directly, answered in a related way by mentioning the idea of the individual being predisposed to respond positively or negatively to different foods. She hinted at the effects some foods are believed to have in the community, whilst rejecting this belief herself:

"Some foods are good for some people and some are not, but it depends. I heard that beef is good, pork liver is good, but some people would say it's not easy to digest. It's very individual. Some old people have old-fashioned thinking. They think that taking lettuce and orange will cause coughing, but this is ridiculous." (F7C, 65-74)

In the Punjabi-speaking group, the concepts of *garam* (hot) and *bhye/ bhaddi* (cold) also refer to innate properties of foods.

"I can't eat very many *bhye* things." (F7P, 65-74)

Exercise was seen by all groups as having an important positive effect on health

"Exercise is very, very important. When you're younger you can do more strenuous exercise, when you are older you need to take it more easily but it's still important." (F4C, 45-54)

"Exercise, weight control is better, a little exercise...10 to 15 minutes everyday, not harsh." (F3P, 55-64)

"Exercise itself is health (*seth*). The movement of every joint makes you fit...in a person's life this is very good for his health." (M8P, 55-64)

"I still play five a side football, and that keeps me going, it's only twice a week, but I believe that exercise can help your health, you know." (M3E, 45-54)

Participants from all groups expressed their belief that psychosocial factors can have a positive or negative effect upon their health:

"If a person is pessimistic, it will affect your health. If you are more optimistic, your health is better, you have more fight for life." (F4C, 45-54)

"I personally think it [ill health] is because of thinking too much (*soch*)" (F2P, 45-54)

"If you're not feeling well and you get depressed and the more depressed you get the worse you feel, it's self-perpetuating." (M15E, 65-74)

Participants from all groups also mentioned specific stressors that could influence health. For example, work stress or satisfaction was seen as being an important factor in health; in the Pakistani and Chinese groups this tended to be expressed by the men:

"If the working and resting hours are appropriate it will help the overall health. No excessive working hours." (M1C, 45-54)

"My thoughts are, don't work too much, reduce your 'hours', don't work 'hard' more than your requirement. You get 'stressed'. 'Stress' is due to 'heavy work' and 'family problems'. With *soch* (thinking) it affects your 'body'." (M8P, 55-64)

"I think generally in Britain we are taking our work more seriously and I see it more and more now, getting uptight...it drains you and then obviously you're more susceptible to minor ailments that come along." (M17E, 45-54)

In contrast, one English-speaking participant expressed scepticism that work-related stress was a legitimate cause of ill health:

"I think stress can affect health, but I think it may be overrated a bit these days, I think it's maybe given as an excuse for an awful lot of things...there are so many people off work with stress, and I'm a bit sceptical about all that." (F2E, 45-54)

Family relationships and circumstances were also viewed as having an important effect on health, although this theme was expressed more often in the Punjabi and Cantonese groups than the English-speaking group:

"Sometimes my children can make me angry or anxious which can affect my health. Sometimes they make you worry or think too much. You just have to learn to let go, to take things easy, there's no other way." (M10C, 65-74)

"Domestic life, particularly 'problems' with children, wife- all these things affect your health." (M8P, 55-64)

"[I've been healthy] because I was happy. There were no fights or disputes with the children or husband and that keeps you healthy. I always was happy because no-one ever rejected what I said...now [due to son-in-law's death] I've had three attacks. [This is due to] definitely my thoughts and my worries. My sorrow." (F17P, 75 or over)

"Family problems are bound to affect people's health because it leads to stress and strain." (M11E, 75 or over)

One Cantonese participant expressed the detrimental impact of negative social relationships on health:

"Hatred. Despising someone will affect your health. Be relaxed." (M5C, 65-74)

Other participants emphasised the necessity of being active and not socially isolated:

"Staying happy. Try to keep occupied, go for walks, wearing good, eating good, putting worries away, seeing friends." (F7P, 65-74)

"Get out and about, seeing people...I think that's important." (F10E, 55-64)

Participants from all groups, apart from the Pakistani women interviewed, mentioned smoking as a factor in determining health:

"Nowadays people are talking about banning smoking altogether because second hand smoking can damage your health." (F6C, 55-64)

"I'm careful about my health. I avoid smoking. My health started to decrease when I started smoking a few cigarettes. My health got better when I stopped." (M8P, 55-64)

"Anybody who smokes realises it damages your health, there's no doubt about it." (M3E, 45-54)

Similarly, drinking to excess was mentioned, but not by any of the Pakistani women participants and by only a small minority of the Pakistani men:

"Yes, drinking too much is not good." (M8C, 45-54)

"Over-drinking will probably not help your system." (F4E, 65-74)

However, some participants were aware that drinking in moderation might be beneficial to health:

"Drinking, as long as it's moderate, for example a glass of red wine, it's good." (M16C, 45-54)

Smoking and drinking were sometimes mentioned together:

"Don't 'smoke', don't 'drink'...[these behaviours] increase illnesses (*bumari*). 'Cigarettes' are 'cancer'. 'Cigarettes' and 'drink' destroy health." (M6P, 55-64)

"Most people know that cigarettes and alcohol are bad for you. It's damaging to your whole body, liver, lungs." (M13C, 75 or over)

Cantonese participants associated these behaviours with a dissolute lifestyle, which included activities such as gambling and playing mah jongg late into the night:

"Don't gamble, don't smoke, no coffee, no alcohol, don't stay up late..." (F14C, 55-64)

One concept present in the Cantonese participants' view of health was that of *chi* or *hay*. *Chi* is the body's energy, or flow, and factors that disrupt or attack the *chi* were viewed as having a negative impact on health:

"Don't get *lo hay* (overworked chi). Don't get over-stimulated/ shocked/ over-worked up/ irritated." (F15C, 75 or over)

"Because of old age I'm less *hay pa* and I get pain more easily. Old people get illness because they have less *hay pa* (chi)." (M3C, 75 or over)

"Having operations damages your chi (*hay*) so I'm glad I won't have to have a third operation." (M16C, 45-54)

"If family or kids are not listening to you, *gik hay* (your chi is being attacked) [and it will affect your health]." (F5C, 45-54)

A minority of participants mentioned the role that heredity and genetics can play in causing ill-health:

"If parents have illnesses like diabetes or asthma then it can affect the children's health." (M8C, 45-54)

"Definitely [I think genetic factors can affect one's health]. For example when I saw the doctor about my heart problem, I was asked if there were any heart problems in the family." (M16C, 45-54)

"I think [genetics] is probably the biggest factor of the lot." (M15E, 65-74)

Only one participant mentioned sexual health:

"...sleeping with too many partners, you can catch AIDS, drugs, if you inject." (F6C, 55-64)

Participants from all groups spoke about the impact of the environment on health:

"Living environment. For example, if the place is dirty and the air's not fresh, polluted. In this modern era there's new things, nuclear power stations, etc. If you live near a dump site, there is toxic air." (M14C, 45-54)

"Also the 'environment'- too much smoke, too dusty." (M7P, 45-54)

"Air pollution maybe in some centres, big cities." (M11E, 75 or over)

Some participants mentioned the inevitable effect of increasing age on health:

"Age...40 plus, there are changes in you." (F2P, 45-54).

"It's my age now, and when you're of my age you have this normal wear and tear in your body." (M10P, 55-64)

"I have a few aches and pains which are probably accepted as things you incur when you get older which you accept and have and that's it." (M17E, 45-54)

Some Cantonese and Punjabi participants, but no English-speaking participants, mentioned climate as influencing their health:

"Whenever the weather's not good, not warm enough, I get pain [rheumatism]. Whenever it happens I keep warm and the pain will go away." (M4C, 65-74)

"The arthritis (*fung sa*- lit. 'wind damp') is caused by wind." (F12C, 65-74).

"My joint pain is due to the cold weather, when I go to Pakistan I feel a lot better." (F7P, 65-74)

Particularly when mentioning their good health, Pakistani participants were more likely to mention God as granting good health:

"Thank God for the health he has given me... Your health is God-given." (M13P, 45-54)

### **5.2.3 Concerns about health**

When asked if they had any concerns about their health, some participants from all groups seemed positive and not overly concerned:

"Generally, I have no worry about my health. During my urinary infection, I was a bit concerned. But I am confident about my health, no worry at all." (F4C, 45-54)

"No I don't have any concerns. As long as you keep a good lifestyle." (M14C, 45-54)

"Not really, no. I don't spend my life worrying about it, I've other things to do." (F5E, 45-54)

Some participants expressed a stoical view of their health and the future, emphasising the futility of worry, sometimes despite chronic disease:

"You can't really worry too much about it. If you get ill you see the doctor and get medication, and if you die you get buried and that's it." (M3C, 75 or over)

"As far as I'm concerned [my pulmonary disease is] a fact of life and you've got to accept it although there's nothing much you can do about it, so there's not much point in worrying about it." (M15E, 65-74)

Some participants who expressed no health concerns attributed this to the calm and acceptance that comes in old age:

"I'm so many odd decades old now. It's not easy to reach 70, so I've no worries. I've reached an old age, so even if I go, there's no regret, but I still want to stay in this world a while longer." (F16C, 75 or over)

"I've lived enough and I'm not bothered to go and have all these check-ups again. I'm not scared of dying and that thought is always in my heart." (M12P, 75 or over)

"No, not really. I feel I've got to this age where, I mean, anything happens to me now, well I just cannae help that, you have to put it down to old age." (F6E, 65-74)

In contrast, other participants were aware that as they got older they were more worried about the possibility of ill-health that accompanies old age:

"When you get old, then you are worried about your health. You will have worry and discomfort all the time." (M12P, 75 or over)

"I mean obviously as you get older, you worry that things start to give way a bit." (F2E, 45-54)

For some participants, particularly some of the women, their health concerns were related to being left alone, dependent, or in an unsatisfactory environment:

"I'm not afraid of dying. I'm worried about being in-between. The worst think would be to go into a nursing home. In a nursing home, I can't speak the language and I can't eat the food. I am *tam* (sad, miserable) at my overall situation." (F3C, 65-74)



"I just worry about being old, no-one to take care of me." (F13C, 75 or over)

"When the children all get married I will be left on my own, so if I have health it's the only way I'm going to survive- who's going to look after me?" (F2P, 45-54)

"The only thing is if I couldn't manage to cope, if I couldn't manage to do things for myself, I'm very independent...I wouldn't like to be in bed, and unable to cope, that's not life." (F16E, 65-74)

Other health concerns were most commonly associated with current medical problems:

"I am worried about my liver, my doctor told me that I had a problem...hepatitis B, I think, a carrier." (F5C, 45-54)

"Yes I am concerned [because of the diabetes] so I do regular checkups." (F16P, 55-64)

"When I'm healthy I'm happy, when I'm not well it is a concern for me, then I get worried. I'm a bit concerned for my health over the past couple of years." (M11P, 75 or over)

Diabetes emerged as a particular issue for some of the Pakistani women interviewed; some were comfortable that their diabetes or 'sugar' was under control, but others expressed more concern:

"I worry that it might be 'sugar' is the cause of the pain in my stomach or medicine is the cause of the pain in my stomach. I sometimes I feel I might be going to die, that some day I'm going to die because of the pain". (F15P, 55-64)

Whilst no Punjabi speakers mentioned cancer as a concern, cancer emerged as a concern in the Chinese sample. Project workers confirmed that cancer was viewed as a major threat in the Chinese community and it was often perceived to be incurable:



"Of course I have concerns. I'm worried about cancer and things." (F9C, 45-54)

"Women tend to worry about having breast cancer, cancer or the womb. You just have to hope it doesn't happen to you...some of my friends had breast cancer...it makes you wonder whether I will get it." (F6C, 55-64)

"Cancer. A lot of people if they get illness they are afraid that it's cancer. Most often it's incurable." (M2C, 66-74)

In addition, a few English speakers also mentioned cancer as a concern:

"When you have a pain or something, you think Oh! Now would it be cancer...I think [cancer's] a worry to everybody." (F16E, 65-74)

"Em, everybody, I think, because we learn, because there's so much to be seen and learned on television about health, I think everybody thinks about cancer, it's in everybody's mind, or it comes into your mind." (M2E, 65-74)

Some participants particularly mentioned being worried about being overweight because of the impact it would have upon their health

"I am scared of being fat but at the same time I can't resist eating certain things...if you are fat, a lot of other problems will follow." (M16C, 45-54)

"I'm aware that I'm overweight and I should be doing something about it." (M1E, 55-64)

Smokers amongst the English-speaking group were aware that their current smoking might effect their health:

"Em, maybe that I smoke. My mother died from emphysema, smoking...and my father died with lung cancer. He smoked...So you start thinking, well I'm smoking really heavily and I'm no living a decent lifestyle, I've only got another 10 years. And it's coming closer, ever closer." (M3E, 45-54)

There was a range of opinions expressed on whether participants were concerned about heart disease. Participants currently suffering from a heart condition expressed some concern:

"My knees, my 'angina'." (F2P, 45-54)

"I'm concerned it [angina] might get more serious..." (M13C, 75 or over)

Other participants concerned about heart disease were more likely to have a family history of cardiovascular problems:

"I suppose slightly, yes [it is a concern because my father died of heart problems]. It's not something I think about on a daily basis - I suppose if I think about it it's the most likely way for me to go, probably, but I don't think about it." (F5E, 45-54)

"Oh yes, my mum had diabetes, my dad has heart disease, so you wonder if you can catch it. You worry that you might be infected. Now it's too late [to eat more healthily]." (F6C, 55-64)

However, others were not concerned about heart disease, regardless of a family history:

"My Dad died just of a heart attack...No, no, [it doesn't worry me] it could happen to anybody." (M13E, 75 or over)

#### **5.2.4 Sources of information about health**

Only a few participants were unable to provide any source of health-related information:

"I don't get any information about health" (F5P, 45-54)

In contrast, most participants mentioned a range of sources of health information.

One theme that emerged was that personal or life experience contributed to knowledge about health:

"It's from experience. I started working at 7 years old- I've heard a lot and seen a lot, it's all down to experience." (F8C, 55-64)

"But I think as you get older you get experience." (F7E, 75 and over)

Other common sources of health information identified were family or friends:

"My children give me information about health...I get the majority of my information from friends and relatives." (F12C, 65-74)

"From people I know. I've heard from other people, or I have seen people have illnesses." (M8C, 45-54)

"Speaking to other people...Friends and family or even strangers." (M1E, 55-64)

However, a minority of participants, did not agree that their friends or relatives were meaningful sources of health-related information for them:

"Not much from friends or neighbours. Most of us don't have much education and knowledge." (M5C, 65-74)

Well I would never discuss my health with anyone else...unless it was something very very minor, you know if I had a sore throat." (F2E, 45-54)

A theme that emerged in all groups was that information about health was often gained via the media- through television, magazines, newspapers, and in one case the internet:

"I suppose that you get information all the time from newspapers and maybe magazines and obviously there are always things on television about them, the usual things about health, so you're bound to pick up a lot of information that way, just by accident really." (F2E, 45-54)

"Information on the internet." (F12E, 45-54)

"It's my own thought but I have also read in books. I read about smoking in a book. Also 'magazines', 'newspapers'." (M7P, 44-54)

"I watch TV, health programmes. Books- I read remedies books." (F16P, 55-64)

Some Cantonese participants specifically mentioned the Chinese satellite channel that most have in their homes, and which is available at the elderly Chinese residential complex:

"Magazines, health columns...from the Chinese channel on TV, I wouldn't be able to watch in English." (F1C, 55-64)

"Reading books, newspaper, TV, both English and Chinese channels. TV is a good way of letting people know about things, especially uneducated people." (M4C, 65-74)

In addition, there were some participants from all groups who did not agree that the media were a main source of health related information:

"I don't read much about medicine [or watch health programmes]." (M5E, 75 and over)

"No, not from TV. I'm a practical person, I can only believe something when I've experienced it." (F16C, 75 and over)

In some cases with Chinese participants, this was due to a lack of literacy:

"I can't read newspapers or magazines." (F13C, 75 and over)

"No [I don't get any information from newspapers or magazines], I've been to school for only one year so I don't know very much Chinese. I can't speak English." (M5C, 65-74)

"Books? Newspapers? Magazines? I don't [can't] read." (M11C, 65-74)

A couple of English speaking participants mentioned their local library as a source of information about health:

"No [my wife] got [videos on health]...from the library." (M2E, 75-74)

"Most recently, with angina being diagnosed, I looked in the local library." (M7E, 55-64)

The majority of participants in the English and Cantonese-speaking groups did not see their GP as a source of health-related information:

"I probably don't get very much information from the GP but I mean that's not anything against him... I wouldn't expect that's something that's his responsibility, really." (F2E, 45-54)

"I suppose if you made a point of going to the surgery and reading all that's there, but who does that? [laughs]" (M14E, 65-74)

"No, not much information from the GP." (F5C, 51)

"No. You go to see the doctor about certain illnesses so they only concentrate on that." (M13C, 78)

In the Cantonese interviews, the language barrier was cited as one of the reasons this might be the case:

"If I'm in Hong Kong, I'd ask [the doctor] a lot of questions, but in the UK, I only ask questions I am able to." (M1C, 49)

"No...there is a language barrier unless an interpreter is there to help." (M13C, 78)

One participant had many suggestions for GPs to give more information to Chinese people:

"It would be good if GPs could give more information, for example dietary advice, and printing out leaflets in Chinese would be useful. For the younger generation it's OK as they are educated and told these things- but for people of 50, 60- we're useless at these things. If this can be achieved then not as many people would need to go the GP. But for us, the older people, we didn't know and would eat things and by the time we found out we had high blood fat it's too late." (F6C, 55-64)

However, a minority of the English speakers did state that their GP/ surgery was a source of health-related information:

"I get a lot of information from [my doctor] really." (M11E, 75 and over)

In comparison to the other groups, a dominant theme that emerged from the Pakistani men was that their GP or doctors in general were sources of information about health:

"It's available from your surgery and particularly from your doctor." (M12P, 75 and over)

"Hospitals, health centres, doctors. That is when you have *bumari* (illness) and you ask about it." (M13P, 45-54)

Although one participant disagreed with the above view:

"Who do we ask? There should be a person who tells us how to look after your health. Doctors don't have time- they just give you medicine and send you away." (M8P, 55-64)

Amongst Pakistani women, whilst a few stated that doctors were their main source of information, attending community groups and community health promotion initiatives was also a dominant theme:

"I learn from [community group]. People come and tell about health here." (F12P, 45-54)

"There are 'seminars' about all the illnesses. We got so much information. It was arranged by MEHIP [Minority Ethnic Health Inclusion Project], even people who didn't have transport they sent taxis to pick them up. There were sessions about every illness, about heart, why do you get angina, how is this caused, precautions. The second week was about diabetes." (F11P, 55-64)

A few of the Pakistani men mentioned also mentioned community groups:

"Our own organisations. If you go to the Pakistan Association. If you go there they have all the information. It is available in our mother tongue [Urdu]." (M10P, 55-64)

Some participants provided a commentary on problems with disseminating information in their community, and sometimes suggested solutions:

"The kind of women who cannot speak English should go to these seminars. You have to give the information to those kind of people, tell them there's information in Urdu or Punjabi, so they can take advantage...there is the MELA and we know there are a lot of Punjabi speakers there, so we could get pamphlets printed and give them there. There were so much arrangements, even taxis, and there are a lot of facilities that people can use." (F11P, 55-64)

"I think the most effective way of 'information' is leaflets. When you read those leaflets you should discuss with your doctor...The leaflets are available in other languages as well, in Urdu." (F16P, 55-64)

"I think personally, our people, men and women, a lot can't read English, or even Urdu or Punjabi. The only way is going to a group, talking to each other, overcoming their problems, releasing the tension and finding out things from others as well. There are women who don't know what goes on in life...there was a woman who didn't know what a 'smear test' was...she said the doctor never told her." (F18P, 45-54)

Amongst Cantonese speaking participants, despite many organised health-related seminars and talks in different community groups within the Chinese community, only one person spontaneously mentioned this type of talk as a valuable source of information health matters:

"Very often I attend these health talks, I only go [to the community group meetings] if there's health talks." (F14C, 55-64)

Some others, once probed, said they did attend or had attended such talks:

"In the Chinese Elderly Support Group, very often they have health talks and I can get a lot of information about that." (M7C, 65-74)

In contrast, some participants denied, or had forgotten, ever having been to a health talk:

"I've never been to health talks." (M11C, 65-74)

Others were aware of health talks and but either did not go regularly or were sceptical of, or ambivalent to, these talks:

"[I don't go to health talks] a lot, but there is the lunch club on Thursday. But most of these talks are general not detailed." (M4C, 65-74)

"I know there are health talks, somewhere and sometime, but I don't go. If I had time I would go. It's always better if it's in Cantonese." (F10C, 45-54)



### **5.2.5 Summary of general health issues**

Overall, participants from all groups spoke in a similar way about general health issues, although English-speakers were particularly likely to speak positively about their health. Whilst there were some indications of culture-specific constructions regarding health, such as the Chinese and Pakistani conceptual division of foods into those with hot and cold properties, and the Chinese concept of *chi* or 'hay', these are unlikely to have a major effect on Rose Angina Questionnaire responses. There were a variety of individual differences in health beliefs and experience. Some, such as general health-related anxiety and concerns about heart disease, may influence an individual's response to the Rose Angina Questionnaire. This is discussed further in Chapter 8.3.1.

## **5.3 Results: Angina and coronary heart disease (CHD)**

Awareness of the conditions of angina and heart disease, and their symptoms, mechanism, causation and sources of knowledge were investigated to ascertain if the concepts existed, or were similarly constructed, in different languages and cultures.

### **5.3.1 Understanding of angina**

In Cantonese, the term angina is translated as *sum gau tung* (literally 'heart twisting pain'). The Pakistani project workers were of the opinion that no equivalent exists in Punjabi so the English term was used. A few people from all ethnic groups had never heard of angina. Others said they were aware of the term but were unable to give much further information about it:



"I've heard the name but I don't know what it means." (F16C, 75 or over)

LH: Is it related to any organ?

"No. To be honest, I don't know." (M13E, 75 or over)

Most participants were able to relate angina to the heart:

"Angina is 'heart problem'...I don't know any more than that" (F15P, 55-64)

"I know it's something to do with the heart." (M15E, 65-74)

Others supplied further information about the mechanism underlying angina:

"The veins in your heart get narrow, the blood through that...[doesn't flow properly]." (F9P, 55-64)

"It's pain caused I think by narrowing of the arteries supplying blood to the heart." (F5E, 45-54)

Despite relating angina to the cardiovascular system, some participants' perceptions of angina were not biologically accurate:

"One or two valves of the heart are closed." (M5P, 45-54)

Some Cantonese participants mentioned the stomach rather than the heart. This is particularly surprising given the inclusion of the Cantonese character for 'heart', *sum*, in the word for angina, *sum gau tung*. No Punjabi or English-speaking participants identified angina with the stomach.

"I've heard of it but I've not had it, it's like stomach ache, it's to do with the stomach. You've eaten the wrong thing." (F14C, 55-64)

"I have this problem with my stomach. But to this day I don't know if it's my stomach or my heart. It comes if I am tense or under pressure or lifting heavy things or in a hurry. The GP sent me to hospital and they did tests and said I have angina (*sum gau tung*)."

"I've not had the experience, so it's hard for me to describe it. Probably it's like cramps in the stomach (*wai chau gung*), and a pulling sensation (*chau ju, chau ju*)." (M15C, 55-64)

One Cantonese participant also interpreted angina as a psychological condition:

"Unhappiness, discomfort (*ng su fo*)...something caused you to feel irritable or angry/ to receive some type of irritation/ to be negatively emotionally affected." (M5C, 65-74)

### **5.3.2 Symptoms of angina**

Some participants were unable to describe the symptom or sensation of angina.

"I don't know...I've never heard of it." (F15C, 75 or over)

"Symptoms-I don't know." (M17E, 45-54)

Others were able only to identify angina with chest pain with no further elaboration:

"All I know is angina is a chest pain." (M13E, 75 or over)

Some participants described the biomedical definition of angina as pain in the chest, arm or jaw:

"Pain in the arm, no sensation in the arm. It doesn't matter if it's left or right. It is left. She feels her arm so heavy she can't lift it up and then feels the pain there [gestures to upper left chest]." (F7P, 65-74)

A number of participants spoke about breathlessness as a particular symptom of angina in addition to pain:

"It's strange (*ajeeb ji*). My heart goes 'tight' and I become breathless, have difficulty breathing." (F2P, 45-54)

"The symptoms are this really gripping pain in the middle of your chest, and I think it's associated with a shortness of breath as well. Not being able to catch your breath. Getting the feeling that you're not getting air to go down deep into your lungs and things like that." (M27E, 45-54)

"If you have pain in the arm, back of neck, or if you go upstairs, pain in the chest or breathlessness". (F16P, 55-64)

Some participants tried to describe the pain associated with angina. There was a range of descriptors used in each language group. Most English speakers found angina difficult to describe, and merely used a primary descriptive term such as 'pain' or 'sore', whilst one man referred to his angina as a sensation:

"I've always described it to my doctor as more of a sensation than a pain, I've never had pain, more of feeling that I was walking too fast, or that I wouldn't, didn't want to walk any further." (M5E, 75 or over)

A minority of English-speaking participants used additional secondary descriptive terms such as gripping or squeezing- for example:

"Well, it's sort of...I find pain quite difficult to describe, you know [laughs]. I suppose a sort of squeezing sort of pain I suppose is the best way to describe it." (F5E, 45-54)

The most common descriptive term used in the English group was 'tight':

"I've always heard of...angina pain as a sort of tightening across the chest, or pains in the shoulder or pains down your arm..." (M26E, 65-74)

"...a tightness in his chest...sometimes he'd talk about the pain in his arm. Classic symptoms." (M16E, 45-54)

Tightness was also mentioned as an angina symptom by some Punjabi participants, often using the English word:

" 'Heart pain', more or less. 'Arteries narrowed'. The 'circulation' does not easily flow...my chest (*chatti*) is 'tight'. I have tightness, discomfort in my arm, and my chest (*seena*) is locked." (M6P, 55-64)

Other examples of pain descriptors used by the Punjabi speakers are:

"*Kich* (pulling). I feel 'tight' in my *chatti* (chest)- it's as if something's pulling (*kick enee*). " (F2P, 45-54)

"*Dard* (pain). All of a sudden I had pain in the *seena* (chest)... *jubka* (pulling pain/ cramp/stab) which was severe." (F6P, 65-74)

Cantonese speakers used a wide range of descriptive terms for angina. A common term was *lau ju* (wringing) or *lau ju tung* (wringing pain). For example:

"It's a kind of heart disease symptom- a wringing, twisting pain (*lau ju tung*)" (M1C, 45-74)

A variety of other pain descriptors were also used:

"The heart has a twisting, stirring pain (*gau ju tung*)." (M12C, 75 or over).

"My aunt told me it was grabbing, tight (*hum hau la ju*)." (M14C, 45-54)

"When it comes I feel very dizzy, my heart was nipping (*la ju, la ju*)...it's very difficult to describe...the feeling is floating/lightheaded (*peel peel yin*), and my heart will start beating a bit faster, there will be a small degree of pain and it was increase gradually." (M7C, 75 or over)

A stabbing, cutting metaphor was used in both Cantonese and Punjabi:

"Like a knife stabbing into the bone- I've heard from someone...knife, needles, stabbing the heart." (M4C, 65-74)

"My pain (*takleef*) was in my chest (*chatti*) and back. It was the kind of pain that was like being cut up/ as if someone was knifing you...As if someone had a knife and was cutting me up from the inside. It was so severe (*zabardust*) I can never forget it." (F11P, 55-64)

Beliefs about factors precipitating angina emerged, and most mirrored Western clinical knowledge. However, there did appear to be some gender difference within the Cantonese group in terms of their medical knowledge of angina; no women discussed the biomedical aspects or presentation of angina, whereas many of the Cantonese men did. Whilst participants from all other language/gender groups spoke

about angina being precipitated by exertion, or walking uphill, some participants attributed the onset of angina to stress, tension or busyness- for example:

"I had it when I was playing mah jongg- I was *sek nu* (tense/ expectation/ excitement)." (M1C, 45-54)

Participants also spoke about the necessity for medical assistance, diagnosis and treatment of angina:

"...they gave me tablets...and they give me some spray to use under my tongue and if you don't get better within 10 minutes you must call a doctor." (F9P, 55-64)

"If I did get angina, I'd ask the doctor to put me to the hospital, shove me on a treadmill with ECG." (M16E, 45- 54)

### **5.3.3 Cause of angina**

A few participants from all groups, some of whom had angina themselves, revealed a lack of knowledge concerning the cause of angina:

"I don't know why it happens or for what reason it happens...the doctor didn't explain to me why I got it...you get discomfort (*takleef*) and pain (*dard*) but I don't know why you get it." (F2P, 45-54)

One participant, despite being diagnosed with angina, reported that no further information had been explained to him, or he was unable to understand the doctor's explanations, as he had no knowledge about his condition and was very concerned about it:

"I'm concerned it might get more serious...I would really like the doctor to tell me how to avoid angina and to this day I don't know the cause and nobody has explained it to me... as far as I can recall [the specialist at the hospital] didn't tell me the cause and I didn't think to ask." (M13C, 75 or over)

However, several people were able to identify classical cardiovascular risk factors related to angina. Diet was most commonly mentioned, with a few individuals additionally mentioning cholesterol and exercise:

"Fatty food, eating too much, little exercise...will cause angina." (M14C, 45-54)

"It's the kind of food we eat." (F6P, 65-74)

"I think they'll tell you its cholesterol. Or lack of exercise." (M2E, 65-74)

One Punjabi participant identified diet as a risk factor, but within a framework of traditional cultural beliefs about the properties of foods. *Bhye* or *bhaddi* was described by project workers as a 'cold' property of foods such as potatoes, dahl, or beef:

"It could be because of eating too much *bhaddi*." (F6P, 65-74)

Very few participants mentioned smoking as a risk factor for developing angina. No Cantonese participants and only one female Punjabi participant and one male English speaking participant suggested smoking as a possible cause. A couple of the Punjabi participants related angina to diabetes, for example:

"My wife is diabetic and due to that she is suffering with the 'angina'." (M12P, 75 or over)

Other possible causes identified in a minority of participants included hereditary factors:

"I have it in my family history (*khandan*)...my father had a heart attack 10 years ago". (F2P, 45-54)

"Hereditary." (M7E, 55-64)

Whilst one Punjabi female participant thought there was a mechanical cause for her husband's angina:

"He was hit in the chest when he was at the restaurant." (F4P, 55-64)

Only one participant, an English speaking woman, suggested that men were more at risk of angina than women were.

### **5.3.4 Source of information about angina**

A common source of information about angina, particularly in the Punjabi and English-speaking groups and to a lesser extent in the Cantonese group, was either personal or familial experience.

"My father had a heart attack. He had angina for 5 years before he died and he just talked about that." (M16E, 45- 54)

"Because my husband had it." (F4P, 55-64)

"I accompanied my mother-in-law to 'casualty'...the doctor said she had 'angina'." (F7C, 65-74)

Several Cantonese and English speakers mentioned the media as a source of information.

"I guess I've read it in papers or books...I've read articles about people getting angina and dying." (F6C, 55-64)

"Paper, TV, I've come across the term *sum gau tung* (angina) there." (M1C, 45-54)

"I've also read magazines, read books as well, I watch television, and if you're watching maybe on the telly, they'll mention things like that." (M16E, 45-54)

However, only one Punjabi participant responded similarly:

"I also read books. Information I get from groups and from TV." (F4P, 55-64)

One other Punjabi-speaking female also spoke about community groups as a source of information.

"In the centre they always talk about this pain in the chest and arm, and if you get it you should call the doctor straight away." (F7P, 65-74)

However none of the Punjabi men or any of the Cantonese participants mentioned learning about angina via community group talks, although there had been a number of these in both communities.

### **5.3.5 Understanding of heart disease**

Participants showed a range of biomedical knowledge about heart disease. For example, one participant had very limited knowledge:

"I don't know...I've heard about it but I can't put it into words...it's something about pain in the chest but I don't know anything about it. I don't know anything." (F13C, 75 or over)

Other participants were able to provide more detailed accounts regarding heart disease, conceptualising heart disease as arising from circulatory problems, often seen as being due to narrowing of blood vessels:

"People say in Punjabi that blood (*khoon*) becomes thick, the heart (*dil*) does not 'pump' the blood. The blood becomes stuck in the arteries/ veins (*nara*). This is what we think." (M8P, 55-64)

"There's a few blood vessels in the heart, and [in my case] only one's working and the others are blocked so they took some from [gestures to thigh]. The heart is like a pump and if the blood can't get through, it's like a car that's stalled." (M6C, 65-74)

"The 'circulation' is not so normal. The blood vessel is blocked and this can lead to 'heart attack' and 'stroke'." (F6C, 55-64)



One Chinese participant expressed similar knowledge, additionally incorporating the Chinese concept of *chi*:

"In heart disease the function of the heart deteriorates and affects your blood flow, your *hoo hay* (blood *chi*)...narrowing of arteries, blocking of blood vessel...overall function of the heart deteriorates..." (F4C, 45-54)

Other types of heart problems were also mentioned, for example problems with the valves in the heart:

"I did have 'heart valve problem'. The cause was when I was playing football and the 2 front teeth loosened out. The dentist gave me 'penicillin' but I threw it away. So when I drank water the bacteria went through my teeth and into my heart. My limbs had a numb feeling, especially in the cold. At the time, I didn't know what the problem was. I saw the doctor and he sent me to the hospital and they found out that all 3 valves of my heart were perforated. When I was diagnosed with a heart valve problem, I had an operation within a few days. They used pig valves. The doctor said if I had the operation I'd have a chance, otherwise I wouldn't last for long. Probably my heart was not working properly and it caused the bad circulation and the numbness in my limbs." (M16C, 45-54)

"I know people can have heart attacks and it's because something goes wrong in their heart, their valves and whatever, but I really haven't had much experience." (F17E, 45-54)

One participant interpreted 'heart disease' to include congenital problems, such as a hole in the heart:

"It's very common, even new born children have it. They have a hole in the heart, it is a very common illness (*bumari*)."

People in all groups were able to speak of biomedical treatment for heart disease, often due to personal or familial experience:

"The 'heart problem' that I have, the main artery, the one that they opened with the 'angioplasty', the 'small artery' has 'narrowed' but the 'consultant' said I don't need a 'bypass'. They've done an 'angioplasty', the balloon that they put inside." (M6P, 55-64)

"I was in London in 1980 and I had a 'pacemaker' in my heart...they told me my heart was not functioning properly and an operation was done." (M12P, 75 or over)

"I know people who have had bypasses, they take a vessel from an animal or a leg." (F4C, 45-54)

One participant may have confused heart disease with *sum tung* (literally heart pain, but metaphorically heartache):

"I think it's genetic, heartache. It's like numb, empty, everything's gone, that's heartache." (F6C, 55-64)

### **5.3.6 Symptoms of heart disease**

Some participants from all groups were unaware of the symptoms of heart disease:

"I personally haven't experienced the symptoms. I've only heard other people talking about heart disease but I haven't experienced it myself. I don't know the symptoms." (M13C, 75 or over)

"No I don't [know what a heart attack would be like]." (F15E, 75 or over)

However, others were able to describe some symptoms of heart disease, the most common being chest pain:

"Well, basically, you know there's the pain in the chest, down the left arm, numbness, tightness in the chest, em, I suppose shortness of breath, that's sort of thing. But it's nothing I've sort of gone into in any great detail." (F2E, 45-54)

"Having heart disease is *ho tam* (very miserable). A lot of discomfort in [pointed to chest]." (F16C, 75 or over)

Some examples of words used to describe the pain of heart disease were as follows:

"My aunt had heart disease...she told me it was *hum hau la ju* (grabbing, tight)." (M14C, 45-54)

"Centre to left of the chest, a sharp stabbing pain, just stopping you in your steps, just the way it's dramatized." (M1E, 55-64)

"Well it's a tightness and it comes on quite suddenly and it's not so frequent now. For a while it was really bugging me because I had to stop doing whatever and just sit and take shallow breaths rather than deep breaths...it was a pain...it wasn't an acute pain, it wasn't pain that would set you screaming, it was just a hard, as if something was out of place, you might say, something had gone wrong." (M11E, 75 or over)

In comparison, one participant believed that pain was not a feature of heart disease:

"There's no pain or any other feeling, just sometimes the heart beats faster. You don't know when it's going to happen. I feel that it happens very suddenly." (M10C, 65-74)

Other participants thought that dizziness might be a symptom of heart disease:

"I don't know...by reading I know that you might get dizziness." (F1C, 55-64)

"Dizziness, unconsciousness...when you develop heart disease, there's always warning signs." (M14C, 45-54)

"[My mother who had a heart attack]... was washing her face, and she took a dizzy turn...and she said, I'd better lie down...And she says, Oh I feel my heart sort of throbbing." (M2E, 65-74)

Breathlessness was mentioned:

"The breathing is tight and hurried and the 'heart' is not good." (F6C, 55-64)

"Well as it got worse I think it would be the tightness in the chest, you tend to deal with that with the inhaler. She [mother] did get quite breathless and she couldn't walk very far." (F13E, 45-54)

"Breathing difficulties and if it's very serious you can die from it." (M12C, 75 or over)

Whilst most participants speaking about heart disease had personal or familial experience, some English speakers had gained knowledge via the media:

"I think that's probably from the television. Or newspapers, or, you know, things that tell you, these are things that you've got to look out for." (F2E, 45-54)

"No, no [no family experience]. It's only just generalities that you pick up on the TV, or in the newspapers on a Sunday, something like that, but specifics, no, I know nothing about it." (M1E, 55-64)

### **5.3.7 Causes of heart disease**

In terms of knowledge of the aetiology of CHD, some individuals had none at all:

"I can't say anything about it. *Dil da* heart attack, it does happen, but I can't give you any cause. It didn't happen to me...I don't know anything about it...I can't say anything about [how to avoid it]." (M11P, 75 or over)

"I haven't the faintest idea what causes them, no doubt there's dozens of reasons, I just don't know." (M1E, 55-64)

However, others were able to cite a range of risk factors. Diet was mentioned most often as having a causative effect on heart disease, with participants sometimes elaborating upon the effect of a high fat diet on blood vessels:

"This is only my opinion and I may be wrong, but too much cholesterol, too much fat, eating/drinking too much, fat blocks up your intestines and then your blood vessels get blocked." (F6C, 55-64)

"Heart disease (*dil de bumari*) is due to eating greasy food. If you eat too much greasy food that makes your veins very narrow." (M14P, 65-74)

"Your diet, I suppose. Your cholesterol, everybody knows that's not good for you." (M3E, 45-54)

Being overweight was seen as being related to diet, and so was seen as a cause of heart disease:

"Bad diet. Obesity...High fat." (F12E, 45-54)

"If you are 'fat', 'overweight'. 'Food, butter'- if you eat this you are likely to get it. Fatty food, butter and oil should be avoided mainly." (M7P, 45-54)

Sometimes beliefs were not wholly accurate:

"The heart is surrounded by fat. Deep fried stuff is not good for you."  
(F14C, 55-64)

One participant held the opposing view that diet did not influence the development of CHD:

"I personally don't think food or diet affects getting heart disease. In general, eating too much meat is not good, but whether or not it affects the heart I don't know." (M13C, 75 or over)

Some participants mentioned exercise as having a cardioprotective effect

"Exercise as well, you should go for a long walk. You do exercise up to the stage that you don't feel tired." (M14P, 65-74)

In contrast, some participants, whilst acknowledging the above risk factors were well-established, were also aware of anomalies, i.e. that having a good diet and taking exercise did not ensure immunity from heart disease:

"Due to 'research', it's the fat of 'greasy food', the 'food' that we eat, the 'fat' is produced and clogs up our 'arteries'. I agree with that, but our theory is OK as well, eat and drink and enjoy but exercise as well. Even if you do all these things, you can still have a heart attack. They say that if you're fit you don't have heart disease but nowadays even athletes, cricketers, footballers have it as well." (M6P, 55-64)

"Although very fit people do drop dead of heart attacks." (F2E, 45-54)

"Well sometimes you see conflicting ideas- some people say watch your weight, watch your diet, keep your exercise up, but from what I've seen anyway, it doesn't matter about the build or the age of the person, it can happen to anyone, so is it just something that just picks on you like that?" (M1E, 55-64)

In addition, some English speakers expressed the opinion that over-exercising or over-exertion could cause heart strain and heart attacks:

"I don't know whether it might be, pushing yourself maybe a bit too far if you do things physically...if ...over-exertion, maybe." (F4E, 65-74)

"And it could be somebody overdoing it perhaps with either exercise or with work, or straining the heart by overlifting and doing things like that." (F7E, 75 or over)

"Maybe you can overstrain your heart." (M2E, 65-74)

"If you've been a man working with heavy materials, heavy work, I would say there's a good reason for a heart attack." (M13E, 75 or over)

Participants from all language groups also mentioned smoking and drinking as behaviours that could contribute to the development of CHD:

"...smoking, drinking..." (F3C, 45-54)

"Don't smoke, if you smoke, blow through a white cloth and you will see a black mark. This will show how bad it is for your 'heart and lungs'. Drink-whiskey, brandy, it gives 'heart problem' because it is strong. Always ask God's forgiveness. Smoking and drinking is a big illness (*bumary*)."

 (M5P, 45-54)

"Well maybe now I've been educated that the heart suffers of course from smoking." (M2E, 65-74)

Psychological and interpersonal stressors were also mentioned by all three cultural groups as having a negative effect on the health of the heart:

"Nervous, being tense, had a trauma, had a fight...normally you don't have heart disease unless you have these things... the heart can't take very much...if you're frightened by anything your heart will beat very fast, your heart is enlarged, blocking your airways." (F8C, 55-64)

"It was caused by...irritation from outside, people getting at me, tension (*gang cheung*)."

 (M1C, 45-54)

"My sister died and that was when I had the second attack. ...It must be [caused] by worry...I already had *takleef* before that but when I heard the news my pain just came upon me".

 (F11P, 55-64)

" 'Stress'. *Zeni takleef* (mind discomfort), thinking too much, serious thinking (*soch, zeni soch*)."

 (M6P, 55-64)

"Doctors say it is people who 'smoke', people who eat too much fat. I think these things are irrelevant and you must be very happy. If a person is ill and thinks too much (*soch*), then they're bound to have *dil de bumary* (heart

illness). Worry (*pereshanee*) is the cause of *dil de bumary*...[To avoid heart trouble] be happy, no worries. *Falaj*, 'stroke' is caused by heart trouble as well. The 'vein' that goes to the 'brain' stops working when you worry too much. This is the 'main' reason." (M13P, 45-54)

"Heart attack can be due to 'depression'." (M14P, 65-74)

"And stress, perhaps...I suppose it depends on the level of stress [laughs]. I don't suppose it would be the only factor, it might be, if there were other factors going on and you were stressed, that might be the final straw type of thing." (F5E, 45-54)

In Cantonese, psychological stress was sometimes conceptualised in terms of the individual's *chi* or energy being depleted and therefore having a negative effect on health:

"Being depressed or overworked/ overtired. Thinking too much, like a build up, something like a knot inside which can cause your breathing to be difficult, *gik hay* (chi attacked)." (F16C, 75 or over)

"The cause of heart disease (*sum chong beng*) is *lo hay* (overworked chi)." (F12C, 65-74)

"*Chi gik* (someone causing a traumatic experience/ pressure/ tension/ anxiety) causes heart disease...I had a tax problem which caused tension/ anxiety." (M6C, 65-74)

Another type of stress mentioned in all groups (more so by the men than the women) was occupational stress:

"...or if you work too hard and too much." (M10C, 65-74)

"The biggest reason is work, style of life. If you are self-employed, you work very long hours, you don't eat properly, you eat at night and go straight to bed, Asian food is full of fat and spices. Business pressure. They don't give their stomach a chance. Not having foods at the right time, doesn't give enough time for digestion. [A solution] would be to employ somebody to give you some time off to rest. But economic circumstances don't allow someone to work for you in small businesses- big superstores are taking over and exerting pressure on small businesses. The more you work, the more wages you'll get." (M2P, 45-54)



"The doctor told my brother in law [who died of a heart attack] to stop riding a motorbike and reduce his work." (M8P, 55-64)

"Well, I should think it was stress, and overwork." (F24E, 65-74)

Some participants from all groups spoke about the effect of heredity or genetics on heart disease:

"Intuitively I think you are born with it, it is inherited." (F9C, 45-54)

"Yes, it might be hereditary (*wai choon*). If a parent has some disease the offspring are more likely to have it as well." (M15C, 55-64)

"In my family we have this *hartack bumary* (heart attack illness). My nephew died of an attack." (M8P, 55-64)

"I'm told, from having spoken to one of the cardiologists, that it's largely genetic. We were talking about diet, and he said, 'Well, an awful lot of it's in the genes.'" (F2E, 45-54)

A few Cantonese participants attributed heart disease to increasing age:

"It's probably an aging problem, aging." (F4C, 45-54)

"Being over 40 years old." (M6C, 65-74)

"When a person's young, under 60, and develops heart disease, it's perhaps lifestyle, like smoking or working, or maybe he's had some type of fright which caused heart disease. If someone is over 60, it's the natural aging of the organ." (M7C, 65-74)

A small number of other participants mentioned other medical conditions as risk factors, such as high blood pressure and diabetes:

"Possibly it would be through having high blood pressure maybe and not picked up." (F13E, 45-54)

"If you are 'diabetic' you are likely to have a heart attack. My wife is diabetic and due to that, she is suffering with the angina. The next cause is blood pressure." (M12P, 75 or over)



Another causes of heart disease mentioned by only two participants was an adverse reaction to medication:

"I went to the doctor and he gave me an antibiotic which I hadn't had before ... and I had this heart business shortly after that." (M11E, 75 or over)

"Tablets for sex gives you 'heart attack'. Your 'body system' goes upside down." (M5P, 45-54)

### **5.3.8 *Summary of knowledge of angina and CHD***

Participants from all groups showed varying knowledge and awareness about angina and heart disease, and associated symptoms, cause, pathology and treatment. Whilst some participants from all cultures were able to provide biomedical explanations of angina and heart disease, others knew very little about these conditions. Participants from all groups mentioned a range of causative factors, for example the role of diet and cholesterol, with psychological stress being seen as an important factor. Most people's knowledge came from personal or familial experience, and some participants had learnt about angina or heart disease via television, books, or magazines. Community-based health promotion was mentioned in a minority of cases. No dominant culture-specific understanding or construction of these conditions emerged; however, a small minority of Cantonese participants associated angina with the stomach. The implications of these findings for the RAQ are discussed in Chapter 8.3.2.

## **5.4 Results: Expression of, and attitudes to, pain**

In order to query whether cultural constructions of pain may affect response to the RAQ, participants were asked to describe their experiences of, and attitudes to, pain.

There was some variation in the way these responses were elicited. Some descriptions and experiences of pain arose spontaneously, or when discussing the participant's general health or pain and discomfort in the chest. Other answers were due to project workers' probing, or to direct questioning. Particularly in the Punjabi-speaking group, the nature of the question varied between the two female project workers who worked sequentially on this project. The latter project worker often chose to ask if the participant had ever experienced unbearable pain. Neither project worker probed much into descriptions of the pain experienced, although this was sometimes explored. Cantonese speaking project workers probed in depth to get the Chinese participants to describe their pain. These discrepancies between project workers' interview techniques will be explored in Chapter 8.2.2.3.

#### **5.4.1 *Categorising and describing pain***

There was some variation in defining what constituted a pain experience, and in categorising that experience. For example, some Cantonese participants mentioned that pain could refer to both physical and psychological sensations. One individual articulated the necessity of understanding mind-body dualism with respect to pain:

"Pain (*tung chaw*) is quite a big topic. There are two aspects of pain- physical (*yuk tai*) and psychological. Psychological is family problems, children. At the minute, I have no psychological problems related to my family. Psychological pain is caused by death and illness in the family. Illness (*beng*) can be the physical side of pain- if I don't bang into something, I won't feel pain." (M1C, 45-54)

Another categorisation of pain emerged in an interview with one Cantonese participant, who divided pain into two types: bone pain and flesh pain:

"The knee pain is a bone pain (*gwat tung*), rather than a normal flesh pain (*yuk tung*). The bone pain is more miserable (*tam*) because it's more internal, deep inside, and the flesh pain is on the surface." (M6C, 65-74)

One English participant expressed his understanding of different terms used to describe pain experiences:

"It depends what you call a pain, because you get aches, you get sharp pains, if I get a sharp pain, you know, I think oh it's just wind in my gut, and usually it is, em, if I have an ache it might be because I've been overdoing it in the garden. Well you get a sharp pain, you go, oh, what's that, you know, a bit like stepping on a drawing pin, but an ache is sometimes a dull throbbing that's there for a while." (M16E, 44-54)

In all groups, a common way of expressing the sensation of pain was simply in terms of its intensity or severity. People gave simple descriptions of the degree of pain or how difficult it was to bear:

"It's just very, very painful, it's hard to describe, I can't say anything else." (F6C, 55-64)

"The operation in the hospital regarding my urine problem, that was *tarp'hna* (very painful, pain you cannot bear.) I was like a fish out of water. I can't forget that pain." (M12P, 75 or over)

"Well the pain of giving childbirth, to be quite blunt, was just bloody awful. It was just painful, it was just incredibly painful." (F2E, 45-54)

A few individuals rated their pain on a numerical scale:

"[Toothache]. It was so severe (*sai lai*), so miserable (*tam*), that if I was to rate it on a scale of one to ten, it was eight." (M14C, 45-54)

"[Sciatica] Ooh, excruciating. On a scale of one to ten, that's kind of nudging ten, at its worst." (F5E, 45-54)

Sometimes participants struggled to describe their pain and described its behavioural effects instead:

"[Pain in chest]. It's just so painful you can't feel anything and you're so frightened you can't speak, and your hands and feet get cold." (F16C, 75 or over)

"It was the type of pain, I couldn't stand, I couldn't sit, my legs were like jelly." (F15P, 55-64)

"I can't sleep at night because of the pain." (M1P, 40-45)

However, there was also a range of descriptive expressions used to describe the type of pain in the different languages. For example, in Cantonese, these were both descriptive in terms of the type of sensation and the regularity of the sensation. Some descriptions directly evoked a motion (*gio ha, gio ha*) and some more metaphorical (like being bitten by ants). Non-word noises and gestures were also used to communicate pain sensation. The following are some examples of terms used:

"The pain of eating too much is a dull pain (*am tung*)." (F7C, 65-74)

"[Childbirth] is *tsang tung* (intermittent pain). It is pain pushed to the limit (*gengk han*)." (F4C, 45-54)

"Pain caused by rheumatism is an aching pain, *soon tung* (lit: sour/acid pain)" (F5C, 45-54)

"I've had back pain- *gil gil ha* (flickering, levering sensation)." (F6C, 55-64)

"[The pain of my varicose vein] is like something being stuffed in, stretched, full and bulgy (*jung ju*) and *chek chek tung* (irritating). *Chik ha chik ha* (like a fishing action)." (F7C, 65-74)

"[The stomach pain] is *gio ha, gio ha* (like trying to get something out from under something)...sometimes if I go to the toilet it *sung sai* (loosens, relieves)...it's *mung ha, mung ha* (short, intermittent pulling sensation). You feel *ng su fo* (discomfort) all over." (F7C, 65-74)

"[Headaches] are *chek ju, chek ju* (irritating, nipping)." (F10C, 45-54)

"I have a bit of mild pain in my breast, it comes and goes. It's like being bitten by ants." (F10C, 45-54)

"[Rheumatism]. It's like *mah bay* (numbness)...it's a kind of pain." (M4C, 65-74)

"[Frozen shoulder]...the pain was so serious, like in the old days we had fish soup and we whacked the fish on the floor- it was like being that fish." (M7C, 65-74)

"The pain in my feet is like a needle-pinning pain. The pain in my breasts is quite similar. They're *tuk tuk tuk tuk*." (F14C, 55-64)

"It's like something growing, something inside is like a small pulling sensation." (F16C, 75 or over or over)

"It's difficult to describe. Stomach *la ju* (squeezing). [makes a throbbing gesture]." (M2C, 65-74)

"[Stomach pain] *Zu zu ni ju* (grabbing, grasping, clawing pain.)" (M3C, 75 or over)

"[Hand pain] It's difficult to describe. I get this numbness (*mah bay*) in my hand, it's a pulling pain (*chau ju tung*), it's the flesh, it's the bone, it's [the inside], it's like needles. [Stomach pain] is *chau ju* (pulling). The heart pain is the most *sun fu* (hard to bear) because when it's painful it's *la ju*." (M6C, 55-64)

"[Back pain] was in the bone (*peng gwat*). *Kio ju* (tangled up action). Also *chi tung* (a sharp pain) and when it comes on you just can't move." (M8C, 45-54)

"[Pain in the buttocks] *Yoon tung* (dull, background, nagging pain) and *chek ju* (pulling) in my coccyx. It's very hard to bear. My right leg will have a pulling pain." (M15C, 55-64)

In English, a variety of descriptive terms for pain were used, such as burning, nagging, dragging, like an electric shock, sharp, dull, stabbing, disabling, gnawing, tightness, searing.

In the Pakistani group, few descriptive terms were spontaneously used by the men, and the project worker interviewing the Pakistani men generally did not probe to elicit further descriptions of pain. However, some Pakistani women did provide

descriptions of pain they had experienced. For example, one participant used the metaphor commonly found in English that her angina was like a knife.

"Yes, when I had 'angina'. My pain (*takleef*) was in my *chatti* (chest) and back. It was the kind of pain that was like being cut up. *Shadeed* (severe) pain. As if someone had a knife and was cutting me up from the inside." (F11P, 55-64)

Another common metaphor in English, burning pain (*jalan*), was also used in Punjabi:

"It was a severe pain and it felt like burning inside" (F16P, 55-64).

Other descriptive terms were as follows:

"It as a *chubcay* (pricking) type of pain, from the back to the front" (F15P, 55-64)

"I feel something is walking/ running about in there [in her stomach]. I feel *ghabra*- my heart is sinking." (F15P, 55-64)

Some Pakistani women chose to use English words to describe their pain:

" 'stiffness', 'sharp pain', 'stiffness in my knees' " (F3P, 55-64)

"My heart goes 'tight'...sometimes you have 'nagging pain', 'weak pain', you 'feel uncomfortable'. (F2P, 45-54)

One Pakistani participant mentioned the pain's variation over time:

"[Back pain] is *agey peechey* (literally, forwards and backwards; means it comes and goes, isn't there all the time)." (M6P, 55-64)

Participants sometimes used both physical gestures (in fact, when trying to translate some of the above descriptive words for the pain, the Chinese project workers were often unable to find an English equivalent or approximation of the phrase and had to gesture with their hands to communicate a sense of the physical action/ sensation

experienced) and noises to communicate their feeling about the expression of the pain. For example, when trying to describe the intensity of reeling from the pain of childbirth, F4C made a whooshing noise, as did M2E:

"That's a pain that you crumble up with...ooooohh- it's like an actual burst, [makes whooshing noise], wow- and that is a pain, it really is. Just terribly painful, really, Oh gee whizz, you're saying Oh, when's that going to stop, Oh! And then it just simmers down and it just becomes a sort of gnawing pain after that." (M2E, 65-74)

#### **5.4.2 Pain tolerance**

Responses varied for self-rated tolerance to pain. [NB: This question was not asked in the Punjabi-speaking interviews]. Some people rated themselves as having a high tolerance:

"I can bear a lot of pain, even though sometimes I'll scream or shout out, I can bear a lot of pain." (M16C, 45-54)

"Well, the doctor does say it's pretty good. The doctor used to say...stoic, is that a word? I can take it, but I find it very irritating." (F15E, 75 or over)

Pain tolerance as something that is dependent on past pain experience was also mentioned:

"I can stand a lot of pain because as a girl I had very severe period pain, I sometimes had to go to A&E, and you get used to it." (F6C, 55-64)

"Quite high. I've had a lot of back trouble in my life so I've had to learn to manage pain because of that." (F5E, 45-54)

There was also a sense of pride in being able to tolerate pain, or alternatively a sense of mild irritation with people who were very intolerant of pain:

"I can tolerate a lot of pain, when I was in hospital the nurse praised me." (F5C, 45-54)

"Oh yes, I can stand a lot of pain, I've had all these operations and never bothered the nurses." (M6C, 65-74)



Other participants said they could bear an average or normal amount of pain:

"If it's severe then I can't bear it but if it's normal then I can bear it." (M10C, 65-74)

"Normal...normal...but I mean I don't know what other people are like...normal for me, but then I've no idea what other people, whether it's high or low compared to anybody else." (F2E, 45-54)

However, other participants were happy to admit they had a low pain tolerance:

"I can't bear pain." (F10C, 45-54)

"My pain tolerance is probably zero, actually I'm presumably like most people I don't want to be in pain, 'cos I don't like pain...I just can't cope with it." (M17E, 45-54)

One individual believed that men were less resistant to pain than women:

"Generally, women can bear more pain than men." (M1C, 45-54)

### **5.4.3 Pain management**

In terms of behavioural response to pain, a few participants expressed the view that pain was something to be borne:

"[Pain from athletics] You have to bear the pain." (M13P, 45-54)

"Well, just had to suffer it." (F7E, 75 or over)

"I know that pain is inevitable as we go through life, and certainly as we grow older. It's quite possible that pain will occur. But I think every individual will just have to cope with it the way they can, the best they can." (M14E, 65-74)

Others' behaviour in response to pain ranged from seeking medical care to self-management. For example, some individuals tried to manage their pain following their doctor's advice:



"The doctor said it was 'arthritis'. The doctor gave me an 'exercise pamphlet'. Sometimes I do the exercises and sometimes I forget, but the *dard* (pain) is still there." (F2P, 45-54)

Some participants chose to use prescription or over-the-counter painkillers to control pain:

"I get coproxamol tablets to take." (F4E, 65-74)

"Oh, just, you know, just the usual paracetamol, aspirin, ibuprofen." (M1E, 55-64)

Others used a variety of non-medicinal techniques:

"I get up slowly. I massage with oil." (F4P, 55-64)

"I didn't want to go to the doctor because he would have given me more medicine and I didn't want more medicine so I used hot water bottle." (F15P, 55-64)

"I have done a lot about [stomach pain]. I have done 'exercise'. I go to hospital and they give me exercises for my stomach. They give me pills. No use. I drink lemon and honey in the morning; it's probably due to this that I'm better. I have changed my diet as well- I don't eat curry." (M9P, 55-64)

"I find that since I went to a chiropractitioner I don't even have to take an aspirin." (F10E, 55-64)

#### **5.4.4 Summary of expression of, and attitudes to, pain**

Participants reported a wide range of pain experiences of varying severity. People from all three groups sometimes found it difficult to describe the sensory experience of pain, describing the functional consequences of the pain or its level of intensity rather than the actual sensation. Cantonese speakers used a wide and varied repertoire of descriptive words to articulate the nature of pain. In relation to overall attitude to pain, there were as many differences within each cultural group as there were between groups. Participants ranged from saying they had little tolerance for

pain to expressing stoical attitudes about pain, viewing it as something one had to tolerate, particularly as one got older. The majority of participants agreed that there was a difference between pain and discomfort, with pain being viewed as more intense and serious, although there were varied ways of articulating this difference. The importance of conceptualisation of pain in relation to the RAQ is discussed further in Chapter 8.3.3 and 8.4.2.

## **5.5 Chapter summary**

The Rose Angina Questionnaire is based on a number of underlying concepts that are rooted in Western biomedicine. Concepts and attitudes relating to health and illness, pain, and the meaning and manifestation of angina and heart disease were shown to vary between individuals. These results showed that there were no dominant themes in the cultural construction of these concepts that were significantly at odds with the underlying assumptions inherent in the RAQ. These findings are discussed further in Chapter 8.3. The next chapter, Chapter 6, presents results from the subsequent stage of the research: to assess the linguistic equivalence of the Rose Angina Questionnaire versions in Punjabi, Cantonese and English.

**Chapter 6      Investigating whether the Punjabi, Cantonese  
and English translations of the RAQ are  
equivalent in each of the study groups**

## **6.1 Introduction**

The preceding chapter presented the findings relating to the appropriateness of the concepts informing and underlying the RAQ in different cultures. This chapter relates to findings from the second stage in establishing the feasibility of using the RAQ in a cross-cultural context, by lay assessment of the translated questionnaire items for understandability and acceptability. In Section 6.2, participants' comments on the translations of the RAQ, as developed by the Newcastle Heart Project, are presented. In Section 6.3, the findings are summarised in relation to the linguistic equivalence of the Rose Angina Questionnaire in Punjabi, Cantonese and English.

## **6.2 Results: Understanding of RAQ items**

As illustrated in the interview topic guide in chapter 4, project workers were instructed to explain to the participant that they were going to be asked if questions were understandable and appropriate. Project workers were to read out each question on the RAQ in the relevant language, and then first, to probe overall opinion on the question and whether the participant could think of a better way of asking the question and second, to assess the understanding of specific words and phrases in more depth.

As can be observed in the results below, project workers did not always follow these instructions exactly, and participants often found the task difficult to comprehend. Consequently, participants tended to answer the question itself rather than comment on its understandability. Project workers also found the task uncomfortable due to participants' lack of understanding. The rigour with which translations were probed

for meaning and acceptability varied between project workers. In some cases this section of the interview lasted just a few minutes. The difficulty found in carrying out and responding to this task is discussed in chapter 8.2.2.4.

Results are presented question-by-question. For each question, overall understandability is assessed, followed by understanding of specific words or phrases, where appropriate. Where perceptions of a word or phrase differ between language groups, results are presented for each language group separately. If alternative or preferable ways of asking the question were suggested by participants, these results are also presented.

#### **6.2.1 RAQ 1a: *Have you ever had any pain or discomfort in your chest?***

Initially, participants from all ethnic groups agreed that this question was understandable, for example:

"I'd say that was pretty straightforward." (F4E, 65-74)

"Quite clear, I understand." (M4C, 65-74)

However, further questioning about specific words and phrases revealed that there was variation in the interpretation of the question both within and between ethnic groups. This will be discussed in terms of understandings of pain and discomfort and understandings of 'chest'. Finally, assessment of the intent of the question shows variation in interpretation.

## Understandings of pain and discomfort

### Cantonese

Pain had been translated into Cantonese as *tung*, whilst discomfort was translated as *ng su fo*. Most Cantonese participants thought that *tung* and *ng su fo* expressed two different sensations.

"They're definitely two separate things." (F8C, 55-64)

However, a minority of participants disagreed, for example:

"No, I don't think there's any difference. No difference. It's the same thing." (M3C, 75 and over)

The difference between the two states was expressed firstly in terms of the intensity of the experience, where pain was seen as more unbearable than discomfort.

"It's different. *Ng su fo* is acceptable; pain is unacceptable. Discomfort is 70% bearable, 30% unbearable- *tung* is the other way round." (M4C, 65-74)

"*Tung* is more difficult to bear than *ng su fo*." (M5C, 65-74)

"*Ng su fo* is more like aching, and *tung* is real pain, very painful (*tung, ho tung*)." (F5C, 45-54)

Secondly, a number of participants mentioned that pain was more serious (*yim cheung*) than discomfort, for example:

"Pain is more serious of course- discomfort is more trivial." (F16C, 75 and over)

"I'd rather have a discomfort than a pain because from my own knowledge and my reading I know that pain is an alarm, but discomfort's not as serious, pain is 'something's wrong'." (F1C, 55-64)

However, one participant thought that *ng su fo* was more serious than *tung*:

"Discomfort can be quite serious, like if you are driving and are dizzy. At least if you have pain you can bear it." (F14C, 55-64)

Sometimes the difference was expressed along a third dimension, the location and extent of the experience. *Tung* was described in localised, physical terms, whilst *ng su fo* could be a more general sensation and include psychological aspects, for example:

"*Tung* is only one place and *ng su fo* can include so many things- it can include breathing difficulties, mental state if it's not happy, worries and concerns, *sum ng su fo* (heart discomfort: metaphor for psychological discomfort)." (M8C, 45-54)

"*Ng su fo* can include if you're feeling worried, anxious, or your mental state." (M13C, 75 and over)

"Chinese people go to the doctor and say they're not well, that can be a lot of things. But if you have a pain, that's specific." (M14C, 45-54)

### Punjabi

Amongst the Pakistani participants, definitions of the two terms were varied and often inconsistent. The Punjabi translation for 'pain' was *dard* and for 'discomfort' was *takleef*. However, the male Pakistani project worker sometimes used the English terms, 'pain' and 'discomfort', having failed to grasp fully the nature of the RAQ assessment task (discussed further in Chapter 8.2.2). About half of the Pakistani participants responded that the two terms had similar meanings, for example:

"As far as I can understand, there is no significant difference between *dard* and *takleef*, some people use the word *dard*, some *takleef*." (M11P, 75 and over)

However, other participants articulated a difference between *dard* and *takleef*. Firstly, as with the other groups, the difference was expressed in terms of severity. However, there were some conflicting views about which term was more severe. Some participants described *dard* as more severe than *takleef*, for example:

"*Dard* is unbearable. *Takleef* is more bearable...*takleef*...could be a *dard* in the future." (F11P, 55-64)

"*Takleef* is little, it's bearable, *dard* is a very, very bad thing...*takleef* is bearable and *dard* is unbearable." (F17P, 75 and over)

However, others said that *takleef* was more severe than *dard*:

"I think if the *dard* gets unbearable it might be *takleef*...if you have a serious problem and you describe it to somebody, that is your *takleef*." (F9P, 55-64)

Secondly, some participants said that the difference was that *takleef* could encompass social or psychological discomfort, similar to the Cantonese term *ng su fo*, for example:

"If your neighbours harass you, you can say that is *takleef* to you. You can't say *dard*." (F4P, 55-64)

"*Takleef* is if you have a friend who's not talking to you". (F6P, 65-74)

"*Dard* is related to illness and *takleef* is when you see someone and you are not happy to see them, you say, I am in *takleef*. *Dard* is 'pain' and *takleef* is illness (*bumari*). *Takleef* is due to illness as well. If someone says something nasty to you, that's *takleef*." (M11P, 75 and over)

Thirdly, some participants spoke about a difference in the duration of the sensation, where *dard* was seen as an immediate response and *takleef* as a more ongoing state, sometimes related to a chronic condition:

"*Dard* can be because of an accident. If you are hurt (*chot*) then you have *dard*. If you have *takleef* it's *lumba* (long; after-effect; lasting effect)." (M2P, 45-54)

"*Takleef* is a prolonged *dard*." (F16P, 55-64)

"A heart patient has *dard* in the arm, but it's not 'pain' it's a *takleef*." (M2P, 45-54)

However, one participant expressed a contradictory view:



"For instance I'm a heart patient, so if I'm not feeling well, the pain I get, I will describe it as a *dard*. Because it is with me all the time and *takleef* is just come and go." (M16P, 55-64)

Another participant said the nature of the difference lay in how discrete or localised the sensation was:

"The 'whole' thing is *takleef*. The word *takleef* refers to the 'whole body'." (F3P, 55-64)

Overall, there was considerable confusion surrounding the precise meanings and contexts of use of the two words, and this was reflected both in participants' statements, often conflicting, and in the project workers' commentary, for example:

"*Takleef* is a lot of *dard*. *Dard* and *takleef* have the same meaning." (M9P, 55-64)

"Whenever there is a pain like a contraction, like appendix pain, people will always use *dard*. We do use *takleef* as well, but not very commonly, but for example these slow sufferers, for example with the heart problem, they would say, I've got heart *takleef*, then they'd use *takleef*...I think every person here, you ask this one person you ask about three times, time to time, three times that person is going to answer different way. Even I can't make my decision...where would I use *takleef*, even though I think, if I really concentrate on it, I think, yes this is *dard*, just a contraction, and if it's a long sort of suffering kind of, you know like you're suffering from the pain of knee or whatever, you think I'm really sort of suffering this discomfort, you think, I'm suffering this *takleef*. But I can't even make up my mind, I can't even make up my mind." (JK, project worker)

### English

All English speakers thought there was a definite difference between pain and discomfort, with pain consistently being seen as a more unpleasant sensation. As with the majority of the Cantonese participants and some of the Punjabi participants, pain was expressed as more severe and more intense:

"To me a pain is something that's concentrated...a pain is more intense." (F16E, 65-74)

"Pain...just knocks the stuffing out of you...discomfort to me is like if you're talking about indigestion...a pain is intense." (F24E, 45-54)

"I wouldn't say a discomfort was a pain...a pain is something that's damn sore." (M13E, 75 and over)

"Yes, I would take discomfort as if you'd get a touch of indigestion or something like that, you know." (M3E, 45-54)

The concept of 'sharpness' as defining the sensation of pain was mentioned by a number of participants, for example:

"I would think pain would be worse than discomfort and is likely to be maybe more sharp sort of pain." (F5E, 45-54)

"Well I always think about pain as something that's sharp and terribly painful as if you wanted to cut yourself open and take it away." (F7E, 75 and over)

Pain was often seen as more intrusive, disruptive and less bearable than discomfort, for example:

"I think pain is something that is really, you know, sort of gets you down, and sort of dominates what you're doing. Whereas a discomfort is something that's maybe just in the background, that you're aware of, that's just in the background rather than very sort of dominating." (F2E, 45-54)

"The pain impacts upon your feelings and sensibilities much more than the sensation of discomfort. If you've got pain, you know it's pain. Discomfort is, well, it's bearable." (M14E, 65-74)

Some participants also saw pain as demanding more urgent attention than discomfort:

"A discomfort you can deal with and overlook and...you know it's going to go away, I guess. A pain is something more important and it would require attention more than a discomfort does." (M11E, 75 and over)

Only one person expressed the difference in terms of the duration of the sensation rather than the intensity, severity and intrusiveness:

"A discomfort I would think would be something that's there for a long time, repeated, recurring. A pain, to me, is just a short, a short span." (M1E, 55-64)

### Summary of understandings of pain and discomfort

Generally, pain was seen as more serious than discomfort, as a more intense experience, and as being more physical, specific and localised, although there was some within-group variation in understanding of these terms, particularly in the Punjabi speakers. In contrast to the English-speaking group, both Punjabi and Cantonese participants identified a psychosocial dimension to discomfort.

### Understanding of chest

#### Cantonese

About a third of the Cantonese women thought this question, in which chest was translated as *hung bo*, was about their breasts, for example:

"When you say *hung bo*, you mean breasts? *Hung bo* refers to breasts because you are asking a female." (F6C, 55-64)

"*Hung bo* is just the breasts." (F10C, 45-54)

However, others did interpret the word as chest:

"I would think chest not breasts." (F1C, 55-64)

"Above the tummy and below the neck." (F4C, 45-54)

Others acknowledged some ambiguity:

"You're not talking about the breasts? *Hung bo* is more internal organs. I would use the word *hung* for breasts." (F6C, 55-64)

"Sometimes breasts could be confused with chest. But I thought this question refers to the chest but not the breasts." (F5C, 45-54)

The majority of the Cantonese men related *hung bo* to their sternal area, most often not verbalising their response but by pointing or tapping their chest. However, one participant did vocalise his response:

"From neck to stomach." (M14C, 45-54)

In addition, however, a couple of male participants mentioned the possible misinterpretation of the word as breasts by women:

"There is a difference between a man and a woman. For me, as a male, *hung bo* is interpreted as heart. If I was female, I'd interpret it as a problem with breasts...breast cancer." (M1C, 45-54)

Another participant did mention that *hung bo* could be ambiguous when applied to a woman, but the topic was too sensitive for him to elaborate. It is possible that this also applied to other men.

Cantonese speakers agreed that the term *sum hau* was a less ambiguous translation of chest in Cantonese. *Hung bo* was seen to cover a wider area than *sum hau*, for example:

"can be very wide, it covers a lot of areas [taps], breasts, 'chest'." (F8C, 55-64)

### Punjabi

The Punjabi translation for chest, *chatti*, was interpreted in varying ways by the Pakistani participants. About half of the Pakistani women interpreted the translated word *chatti* as breasts, for example

"It could be some type of lump...Problems in 'breasts'." (F9P, 55-64)

"It is breasts." (F12P, 45-54)

"*Chatti* is bust." (F17P, 75 and over)

A couple said the meaning of *chatti* was ambiguous, and could mean chest or breasts, for example:

"There are two meanings for *chatti*." (F11P, 55-65)

The term *seena*, another word for chest, was agreed by those asked to be closer in meaning to the area meant by the English word chest in the question, for example:

"*Chatti* is 'breast'...you would have to use *seena*...then you would be talking about heart pain." (F12P, 45-54)

"*Chatti* is my breasts, *seena* is where your heart is." (F2P, 45-54)

When the word *seena* was substituted for *chatti*, many women understood the question better and responded more accurately. For example, F17P had answered 'yes' to the question "Have you ever had any pain or discomfort in your chest?" when the word *chatti* was used for 'chest':

"If you had asked me if I had a *dard* (pain) in *seena*, then I would have said to you no. I never had a pain in the *seena*". (F17P, 75 and over)

"Most probably you are wanting to know if I have a 'heart problem'." (F15P, 55-64)

When the Pakistani men were asked where on the body *chatti* was located, the majority indicated that *chatti* covered roughly the same area as the English word *chest*, either verbally or by gesturing to their sternum:

" 'Front portion' [pointed to middle sternum]. Heart (*dil*) is on the 'left side'." (M5P, 45-54)

Although in one case, the participant's understanding of the area extended further:

"Above your belly button is all *chatti*." (M12P, 75 and over)

However, the project worker did not always ask this question correctly, sometimes forgetting to probe understanding of the term and sometimes asking what the participant understood by the English word 'chest'. However, in this case the male participants produced the Punjabi translation, *chatti*, indicating their understanding. A few Pakistani men interviewed also acknowledged the dual meaning of *chatti*, but as this was a sensitive subject their comments were often non-elaborative, for example:

"You should not use *chatti* when talking to a woman." (M13P, 45-54)

Some Pakistani men mentioned that the word *seena* was also appropriate to use when referring to the chest, for example:

"*Chatti* and *seena* are the same." (M9P, 55-64)

An alternative translation for chest, *hick*, was suggested by two participants in addition to *seena*. This word, *hick*, was not recognised by any of the Punjabi-speaking project workers. One participant agreed that *seena* would be equally understandable and appropriate for men and women, for example

"The proper word in Punjabi would be *hick*. There is a difference between *chatti* and *seena*. *Seena* is OK to use for a man or a woman just like *hick*." (M13P, 45-54)

### English

There was some variation in understanding of the word chest even within the English-speaking groups. The majority of English speakers agreed that the word 'chest' referred to an area in their upper thorax, for example:

"Everything inside the chest, everything inside the ribcage, and just up to where your collarbone goes into your neck- collarbones to the ribcage." (M2E, 65-74)

"I would think of the thoracic region." (F5E, 45-54)

Many did not vocalise their response but gestured from the bottom of the ribcage area to their neck. Some participants, however, thought the chest extended a bit further, for example:

"Say from navel to chin." (M1E, 55-64)

"I would say sort of shoulders to waist, back and front." (F12E, 45-54)

And others saw 'chest' as more restricted, for example:

"Just round about there [points to centre of chest]." (F7E, 75 and over)

In contrast to some of the ethnic minority participants, no English-speaking women interpreted the word chest in this context to be referring to her breasts, even when probed:

"I hadn't thought of that...they're very distinct words in English." (F2E, 45-54)

However, a few participants, including a man, agreed that others may possibly misinterpret the question in this way:

"I think you might get people asking exactly what, you know...they might say to you, "Do you mean indigestion, heart, your breasts?" or whatever, you know, some people might." (F24E, 45-54)

"It makes sense to me...but if you say that to a female she might think you mean her breasts, not her chest. I mean I could quite easily see that being misinterpreted, especially, I mean, I was a biology teacher, and just teaching kids in the class, just basic anatomy, things like that, their idea of stomach and chest were completely different and varied, and some of these kids will continue that throughout life." (M16E, 45-54)

### Summary of understandings of 'chest'

In summary, there was a lack of equivalence between the understandings of the English word 'chest' and the Punjabi and Cantonese translations used in the Newcastle Heart Project- *chatti* and *hung bo* respectively. Some Pakistani and Chinese women interpreted these translations to refer to their breasts; whilst no English-speaking women did so, a few participants, including two English-speaking men, thought there might be some interpretation of 'chest' as breasts. Alternatives in Punjabi and Cantonese were suggested that most participants agreed were less ambiguous and which were closer in meaning to the English word 'chest'. Overall, participants from all groups had varied opinions on the area covered by the word 'chest' or its translations, ranging from a localised area round the central sternum to a more diffuse area above the waist and below the neck, or including the back.

### Overall interpretation of the question "Have you ever had any pain or discomfort in your chest?"

As shown, a number of Chinese and Pakistani women understood this question to be relating to their breasts. Other participants from all ethnic groups were able to relate the question to the heart (including Pakistani women once the translation for chest was changed from *chatti* to *seena*). For example:

"This is *dil dard* (heart pain), it is *hartack* (heart attack)." (M8P, 55-64)

" 'Heart problems'." (M16P, 55-64)

"I would guess you were finding out if the heart was all right." (F4E, 65-74)

"The first thing that came into my mind is that it's related to the heart. The heart is inside the chest." (M16C, 45-54)



However, only a few participants specifically related the question to angina:

" 'Angina', 'heart disease'." (F3P, 55-64)

Some participants were less sure of the meaning of the question but still related it to the heart, for example:

"I don't know anything about it. Sometimes it has something to do with the heart- the only thing I can tell you is it is something to do with the blood. It could be due to your age. If you're not feeling well and you cough a lot, that might contribute to the pain and discomfort in chest." (M10P, 55-64)

"I don't know anything about it...I heard from somebody that when you have pain in your chest you feel a contraction and this is a sign of *dil da dora* (heart attack)." (M11P, 75 and over)

"It could be anything, it could be indigestion, it could be a strain, you know if you've twisted something, something like that, or your heart. Or your lungs." (F16E, 65-74)

"Probably the heart and the stomach." (M7C, 65-74)

A small minority of the participants did not associate the question with the heart but with other body parts, for example:

"You're asking me if I have a stomach or a liver problem." (M12C, 75 and over)

"There could be so many *takleef* inside your body. Could be kidneys, could be liver." (F6P, 65-74)

"Obviously, probably, I think what comes out first is the lungs, you'd think they'd want to find out if there was any problem with your lungs." (M2E, 65-74)

### Summary of interpretation of RAQ 1a

In summary, inappropriate translations in Punjabi and Cantonese lead some women from these groups to believe they were being asked a question about breast pain or breast cancer. Other participants from all groups were able to relate this question to

the heart, but few were able to specify that it might be querying angina. A minority of participants' beliefs were that they were being asked about non-cardiac conditions such as lung or stomach problems.

### **6.2.2 RAQ 1b: *If no, have you ever had any pressure or heaviness in your chest?***

This question is not present in the English or Punjabi versions of the Rose Angina Questionnaire used in the Newcastle Heart Project, but is included in the Chinese version. Whilst a minority of Cantonese-speaking participants said they had no objections to this question, others did have comments on its acceptability. One participant thought that the question should relate more clearly back to the previous one about pain and discomfort in the chest:

"You should elaborate more, instead of just 'If no', you should say 'If no pain or discomfort'." (M4C, 65-74)

A number of participants had difficulty fully understanding heaviness (*cheung lek*):

"I don't know [what it means]." (F3C, 65-74)

"What do you mean by heaviness?" (F9C, 45-54)

"I've never really heard this word being used." (M8C, 45-54)

Others suggested omitting the word entirely:

"Yes, I understood, but there's some ambiguity. What do you mean by heaviness? You could ask directly and say, 'Is there any pressure on your chest?'" (M16C, 45-54)

"You shouldn't say heaviness, just say pressure, if you have heaviness you have some sort of illness." (M4C, 65-74)

"It's problematic...you could say, 'Has your chest ever felt any pressure?'" (M14C, 45-54)

Some participants interpreted the 'pressure' to be psychological and not physical:

"The question has made no point. When you're talking about pain, it's a physical word, but pressure (*aat lik*) is psychological. It should be divided into two questions- pressure, which is psychological, and pain." (M1C, 45-54)

"You have to explain clearly if it is physical pressure or psychological pressure...it's a very difficult question to answer." (M13C, 75 and over)

However, other participants were able to express their understanding of the phrase, often using the image of a large physical weight or using mechanical metaphors:

"Do you mean it's like something obstructing?" (F6C, 55-64)

"Is it like *kok ju*? (energy trapped, going to explode, bursting)" (F13C, 75 and over)

"It's like being restricted, not breathing in." (F4C, 45-54)

"It's like a weight hanging down...something fallen down and pressing." (F8C, 55-64)

"It's like a rock or stone pressing on your chest (*sum hau*)." (F1C, 55-64)

Note that the participant above, F1C, used the phrase *sum hau* for chest in her answer, whereas the RAQ question used the phrase *hung bo* for chest.

The question was misinterpreted as an external sensation caused by a physical object by one participant, rather than an internal sensation:

"That means don't have heavy things pressing on the chest...[pressure] means to put a weight over the chest." (M2C, 65-74)

In terms of suggesting improvements or modifications to the questionnaire, less women than men were able to do so:

"I know it can be improved but I don't know how." (F9C, 45-54)

"It's better to say something, like a rock, is pressing on." (F6C, 55-64)

### Summary of findings relating to RAQ 1b

This question was present only in the Cantonese version of the RAQ. The Chinese participants had various difficulties in understanding this question; firstly, some did not understand the translation for 'heaviness'; others interpreted the translation of 'pressure' to relate to psychological pressure; and in one case the question was interpreted as asking about a physical object weighing on the chest.

### **6.2.3 RAQ 1c: Do you get it when you walk uphill or hurry?**

#### Cantonese

The Cantonese translation of this question was problematic for two main reasons. The project workers rendered this question in English as: "Do you get the symptom when you walk the slope (*tay bo*) or hurry?" Firstly, most participants interpreted the word 'symptom' in the question to refer to something other than pain or discomfort in the chest, such as breathlessness:

"Does that mean you're asking if I'm tired or breathless?" (F13C, 75 and over)

Some participants said they didn't understand what the term 'the symptom' referred to:

"It didn't say clearly what sort of symptoms." (M7C, 65-74)

Others said they thought the symptom referred to the previous question about heaviness pressing on the chest, not, as was intended, the initial question about pain or discomfort in the chest:

"It refers to the pressure and heaviness." (F4C, 45-54)

"You should say the heaviness or the pressure, not the symptom." (M4C, 65-74)

Other participants interpreted the symptom in a more medical sense:

"Is it heart disease?" (F5C, 45-54)

"When you walk fast the blood flows quicker and your heart beats faster and that's the symptom." (M8C, 45-54)

A minority of participants understood that the word symptom referred to pain or discomfort in the chest, but still expressed reservations about the question:

"Probably it refers back to the chest pain, but it's not very clear." (F7C, 65-74)

As noted below, the word 'symptom' does not appear in the English or Punjabi versions.

Secondly, it was found that the Cantonese translation for 'uphill' used in the Newcastle Heart Project version of the RAQ could lead to confusion as it was translated into English by the project workers as 'walking the slope' without specification of direction, and hence may also mean downhill. Some participants had no difficulty in interpreting the non-directional translation for this, *tay bo* (slope) as uphill:

"It means going up." (F15C, 75 and over)

However others interpreted the question as going down.

"*Tay bo* is downhill." (M2C, 65-74; M8C, 45-54)

"It's going down. If you were going up you'd say *sheung au*." (M6C, 65-74)

However, even if they interpreted *tay bo* as uphill, most participants asked agreed that it could also mean downhill and that it was better to specify the direction:

"*Tay bo* is both directions...it's better to say up the slope." (F5C, 45-54)

"You have to say *sheung tay bo* which is up the slope." (F6C, 55-64)

"You have to specify if it's going up or down but if you don't specify it would mean going up more than going down." (M13C, 75 and over)

There was no misunderstanding of the translation of 'hurry', with all participants asked interpreting it as walking faster or more quickly.

### Punjabi

In the Punjabi version, this question was translated into English by the project workers as "Do you get this pain or discomfort when you walk uphill or hurry?"

Most Pakistani participants said that this question was understandable. The translation for 'uphill', *chorai*, was probed in about half of the interviews. Most participants agreed it was an uphill slope (some actually supplying the English translation, 'uphill') but with varying interpretations. Some participants expressed the concept as a slight incline, not mountainous:

"Going up a little-little." (F2P, 45-54)

"When the street goes up a bit." (F3P, 55-64),

"It's not a mountain, it's not *bahar*, going up a hill on a road." (F18P, 45-54)

On the contrary, one participant disagreed, and felt the word expressed a more steep slope:

"*Chorai* is going up the mountain as well...[a slight incline] is not *chorai*."  
(F9P, 55-64)

Some participants mentioned that it was a location:

"A hilly place." (F4P, 55-64)

"A high place." (F5P, 45-54)

Others mentioned going up stairs:

"It could be going up the stairs (*unjai*) as well." (F16P, 55-64)

The translation for 'hurry', *juldi*, was probed in a minority (4 women and 4 men) of the interviews. All responses implied increased speed:

"A brisk walk." (F5P, 45-54)

"When you walk really fast." (M11P, 75 and over)

The women often related this to functional pressure to perform a task or tasks, and either implicitly or explicitly mentioned the concomittant stress:

"If you have to be somewhere at 11 o'clock, you'll go *juldi*." (F2P, 45-54)

"To walk quickly. When you have to do 2 or 3 different things in one go."  
(F3P, 55-64)

" 'Hurry'. 'Stressful'." (F4P, 55-64)

### English

All English speakers understood the question. As mentioned previously, some participants tended to answer the question rather than stating whether they found it understandable or acceptable. However, answering the question sometimes indicated that a participant had understood the question adequately; as can be seen in the following examples:

"I don't really get the pain when I walk uphill, I just have to slow down, but I don't get the pain when I walk uphill." (F4E, 65-74)

"Well that's difficult to answer because I don't really hurry or walk, well walking uphill I have to do occasionally but not from choice." (M11E, 75 and over)

Like the Pakistani participants, English speakers' conceptualisation of uphill varied:

"It doesn't have to be very steep at all, it can just be a wee incline, it just depends how you are." (F17E, 45-54)

"A very low gradient." (M7E, 55-64)

"Uphill to me would be the mountains...the Bridges [street in Edinburgh] would be an incline, uphill." (M17E, 45-54)

"That it's a steep hill going up, and you're puffing and blowing, if you're not fit." (F26E, 65-74)

Hurry was also interpreted slightly differently by different people, although the idea of increased speed was agreed upon:

"Somebody's running. Or not far off it." (F24E, 45-54)

"Not walking at a steady pace. When you're trying to, you know, put a wee bit of spurt on, trying to catch up with your husband because he walks faster." (F17E, 45-54)

Some participants commented on the subjective nature of the word hurry:

"That varies from person to person." (F5E, 45-54)

"To some people, hurrying is running. But to other people just walking quickly is hurrying, or just walking at 3 miles an hour instead of their usual 2 miles an hour." (M16E, 45-54)

### Summary of findings relating to RAQ 1c

This translation was not acceptable to Cantonese participants nor was it comparable to the English meaning. Most Cantonese participants consulted agreed that



clarifying the symptom as pain and discomfort in the chest and specifying the direction of walking on the slope would be make the question easier to understand. Although this question seemed generally acceptable and equivalent in meaning to the English-speaking and Pakistani participants, there was a range of interpretations of the activities involved in 'going uphill' and 'hurry' and thus room for ambiguity in responses.

#### **6.2.4 RAQ 1d: Do you get it when you walk at an ordinary pace on the level?**

There was some variation in the sentence structure between different language versions of this question.

##### Cantonese

The Cantonese version was translated into English by the project workers as "Do you get this symptom when you walk on the level?" The project workers reported that 'ordinary pace' was not translated in the Chinese version, in contrast to the English and Punjabi versions. Most Cantonese participants said that this question was understandable and acceptable:

"I understood. It's very easy to understand." (M13C, 75 and over)

However, as before, there was some confusion regarding the word 'symptom' and to what it referred. Some participants interpreted the symptom to be pressure or heaviness, rather than pain or discomfort in the chest; others said it was unclear, whilst the most common misinterpretation was that it referred to breathlessness, for example:

"You're asking me if I walk on the level do I get breathless." (F15C, 75 and over)

When the translation for 'on the level' was probed, most participants agreed on an understanding that is equivalent to the English:

"Not a slope, flat ground." (F6C, 55-64)

However, a couple of participants said they didn't understand, but it was unclear whether they were referring to the question or the task:

"[No response, silence, laughter]. I don't understand." (M2C, 65-74)

### Punjabi

The Punjabi-speaking project workers translated this question into English as "Do you get pain or discomfort when you walk at an ordinary pace on the level?" Almost all participants said the question was understandable, although often without elaborating further or being asked about their interpretation of each word or phrase. When this probing did take place, most participants understood the word *padhry*, the translation for 'on the level', in a way that was equivalent to the English meaning:

"It's not uphill." (F2P, 45-54)

"You mean 'level'." (F7P, 65-74)

"*Humwaar* (even)." (M8P, 55-64)

In a few cases there was some misunderstanding of the word *padhry*. One participant said:

"I've never heard that word." (F18P, 45-54)

This participant suggested *sidhy*, meaning 'straight', as an alternative. She said that *padhry* was

"*Teet* Punjabi, 'strong' and 'deep' Punjabi."

The word *teet* refers to a pure, traditional Punjabi as spoken in the villages in the Punjab, as opposed to the Punjabi spoken by most contemporary Pakistanis. Despite her lack of understanding of the word as used, this participant was, perhaps, representative of many of the participants in that she was reluctant to challenge the official translations, perhaps considering herself ill-qualified to do so. After making her comments, she was keen to urge her interviewer,

"Don't correct it on your form because maybe it is OK."

Another participant interpreted *padhry* slightly differently from the others, in terms of obstacles on a flat surface rather than the absence of a slope:

"*Padhry* is when there are no ditches or nothing in your way, not if it is up or down hill." (F17P, 75 and over)

Only one participant was asked what they understood by the translation for 'ordinary pace' meant, and they responded

"Walk slowly." (M9P, 55-64)

However, a comment from a co-worker indicates that the project worker carrying out half of these interviews may not have been using the correct Punjabi translation as provided to him at the beginning of the project, as he had failed to understand the need to ask the participants to assess the questions word-for-word as they had been asked in the previous Punjabi translation developed by the Newcastle Heart Project.

This project worker may have been making his own translations, and often substituting Urdu words for the Punjabi equivalent. For example, the following is an example of dialogue between the two project workers when we were translating the interview into English.

Project worker #1: The third one is, 'Do you get this pain when you are walking on level surface?'

Project worker #2: What word did you use?

Project worker #1: It's a Punjabi word. Basically it is in Urdu but is always used when talking to someone.

Project worker #2: Lahore Punjabi! [laughs]

### English

All English speakers found the question easily understandable, sometimes indicating this by answering the question rather than commenting directly on its understandability. A few comments and suggestions were made:

"Again, what's an ordinary pace? There's a tremendous difference in the speed people walk. I don't walk particularly fast compared with some people I know, but I walk faster than others." (F5E, 45-54)

"Ordinary pace...if what's ordinary to one person is ordinary to another...it may be less subjective if you could get somebody to word...what you mean by [ordinary pace]." (M26E, 65-74)

"I would rephrase it and say, 'Do you get the pain and discomfort from walking...' -it's much more specific and there's less chance of you getting incorrect information because people have misunderstood 'it'." (F12E, 45-54)

### Summary of findings relating to RAQ 1d

The Cantonese version of this question was not equivalent to the Punjabi or English as it included the word 'the symptom' and omitted the phrase 'on the level'. Chinese participants were often confused as to the phrase 'the symptom' and did not relate it to pain and discomfort in the chest. Similarly, the English version included the word 'it' rather than specifying 'pain and discomfort in the chest' and it was thought that

the latter wording would be less ambiguous. The equivalence of the Punjabi version to the English was difficult to ascertain as the meaning of words and phrases was probed in only a minority of cases, and the questions may not always have been posed in the Newcastle Heart Project-developed Punjabi, but in the project worker's own words, including Urdu words. This methodological finding will be discussed in depth in Chapter 8.2.2. Some of the Pakistani participants did not understand the translation for 'on the level', *padhry*, thinking this was not the type of Punjabi that they would speak. Regional variations in languages such as Punjabi will be discussed further in Chapter 8.4.1. Overall, there was an indication that individuals may vary in their understanding of phrases like 'ordinary pace'.

#### **6.2.5 RAQ 1e: What do you do if you get it while you are walking?**

##### ***Stop or slow down/ carry on***

##### Cantonese

As with question RAQ 1d above, the project workers reported that the Newcastle Heart Project Cantonese version of this question translated 'it' as 'the symptom'.

Initially it appeared that most participants understood the wording of the question:

"I understand fine. You should stop and rest." (M14C, 45-54)

"No problem, it's OK." (M1C, 45-54)

However, some answers hinted that participants were still interpreting the 'symptom' as breathlessness, as in the previous question:

"You should take a deep breath." (F8C, 55-64)

"You have to stop and rest. It depends if you're wheezing and gasping for breath." (F13C, 75 and over)

As in all ethnic groups, some participants answered this question directly rather than assessing its acceptability or understandability, but in a way which indicated they may have understood the correct meaning of the question:

"You have to stop walking or slow down." (M13C, 75 and over)

However, the above participant may also have understood the 'symptom' to refer to breathlessness, and was answering accordingly.

One participant appeared quite confused, and initially answered the question

"There is nothing to do." (F15C, 75 and over)

When probed further if she understood the question, she responded

"Not quite."

The response choices (stop/ slow down/ carry on) were understood by most participants asked.

### Punjabi

Project workers reported that, in the Punjabi version, this question is worded as "When you get any pain or discomfort in your chest, what do you do? Stop/ Slow down/ continue at the same pace." Overall, most of the participants appeared to understand this question fully, although again a few attempted to answer the question itself, but in a manner that showed they had understood:

"I just sit down or stand there when I get the pain in my chest." (M6P, 55-64)

"The doctor gives me a spray under my tongue." (M15P, 75-74)

One participant again reiterated the misuse of the word *chatti* for 'chest' in the question, and answered the question by responding

"No, I don't get it in my *chatti*, I get it in my *seena*." (F2P, 45-54)

It is possible that the other participants understood the question lexically but continued to misinterpret the translation of chest, *chatti*, as breasts, as outlined previously. Only one other suggestion was made, concerning the translation of the response, *karey*, literally 'stand still', for 'stop'. F4P, 55-64, suggested

"Say *rookjandeyo* (stop) instead of *karey* (stand still)."

However the response options were probed by the project workers in only a minority of the interviews.

### English

In the English version, the question is "What do you do if you get it while you are walking?" All English speakers found the question understandable, for example:

"It's quite straightforward, anyone would know exactly what you are meaning if you said that, very understandable." (F4E, 65-74)

### Summary of findings relating to RAQ 1e

Again, the different language versions were not equivalent: only the Punjabi version specified 'pain and discomfort in the chest', whilst the Cantonese version translated this as 'the symptom' and the English version used the word 'it'. Chinese participants in particular interpreted this question as referring to breathlessness. The Punjabi translation for 'chest' used, *chatti*, shown to also mean 'breasts' in question

RAQ1a above, was again used inappropriately in this question, and *seena* was again suggested as a more appropriate term.

### **6.2.6 RAQ 1f: *If you stand still, what happens to it? Relieved/ not relieved***

#### Cantonese

The project workers translated this question from Chinese into English as: "If you stop walking, how is your chest pain?" "Pain reduced/ still painful". Chinese participants understood this question more accurately than the previous two questions because the 'it' in the English version was translated not as 'symptom' in the Cantonese but as 'chest pain'.

"Yes, I understand...you're asking about chest pain and that's good, it's an OK question." (F3C, 65-74)

A couple of Chinese participants were slightly critical of the Cantonese translation, but without suggesting any alternatives:

"It's understandable, but it's not very good." (F1C, 55-64)

"The translation's not very good, the level of Chinese isn't very good." (M1C, 45-54)

In addition, at this stage some Chinese participants were finding it difficult to maintain understanding of the assessment nature of the task and their answers indicate their confusion:

"After you explained it I understand, but at the start I didn't get it." (M5C, 65-74)

"If I stop walking, I will be ill." (M3C, 75 and over)

"I don't understand your stuff, Miss!" (F16C, 75 and over)



### All groups

Most participants from all ethnic groups said that they understood the question,

"Yes. You asked me if I stop and do you still have the pain." (M13C, 75 and over)

"[That's] reasonably clear." (F2E, 45-54)

As usual, many participants from all three groups answered the question itself, but in a way that showed they understood:

"I don't have chest pain when I walk or when I stop walking." (F15C, 75 and over)

"Well, I have done that on occasion, it gives you a bit of relief, you know, if you're still climbing a hill." (F6E, 65-74)

"The pain goes away and it doesn't increase." (M6P, 55-64)

Of the minority of participants who were asked to express their understanding of the response choices, most understood and some expressed their meanings in alternative ways:

"Not as much pain as before and just as painful as before." (F4C, 45-54)

### Summary of findings relating to RAQ 1f

Overall, this question was translated in a more equivalent way across languages than previous questions, and was generally understood across groups. However, some Chinese participants thought the question was not very well translated into their language, but without suggesting alternatives.

### **6.2.7 RAQ 1g: How soon? 10 minutes or less/ more than 10 minutes**

#### All groups

The Chinese version of this question was translated into English by project workers as: "How long does it take to reduce the pain?" The Punjabi version was translated into English by project workers as: "How soon does it go away?" Most participants from all groups understood this question. Some stated so directly:

"It's very clear, there's no need to do any alteration." (M16C, 45-54)

Others answered the question rather than assessing its understandability, but their answers implied that they had understood the question:

"Maybe sometimes ten minutes, before it goes." (F17E, 45-54)

"Normally it lasts for 5-6 minutes." (M6P, 55-64)

"It just depends, some people take half an hour, some people take a few minutes, it depends how hard to bear it is." (M6C, 65-74)

"In little or no time, 2 minutes." (M7E, 55-64)

The understandability of the response choices (ten minutes or less/ more than ten minutes) was not queried further in the Punjabi speaking group. One interesting finding is that units of time in lay colloquial Cantonese are often given in multiples of five. For example, two participants explained their understanding of the response choices as follows:

"Ten minutes or less is about five minutes." (F8C, 55-64)

"Ten minutes means two five minute blocks, less than 10 minutes means less than 2 five minute blocks." (M5C, 65-74)

### Summary of findings relating to RAQ 1g

This question's meaning seemed to be equivalent across languages; participants from all groups understood the question in a similar way.

#### **6.2.8 RAQ 1h: *Will you show me where it was?***

##### Cantonese

A few Chinese participants suggested a better way of phrasing the question:

"You should say which part of your body, rather than where." (F4C, 45-54)

"It's OK, but it's better to say 'which part' rather than 'where'. In which part of your body is your pain?" (M14C, 45-54)

However, some Chinese participants were confused and tired by this stage, and said that they did not understand, although it may be that they were referring to not understanding the whole RAQ assessment task, rather than the actual words of this question (M2C, 65-74; M10C, 65-74; M11C, 65-74.)

##### Punjabi

Project workers rendered this question into English as "Where do you get this pain or discomfort?" Most participants from all groups seemed to understand the question without any misinterpretation:

"It's very clear. There's no need to alter anything. If you just answer the questions one after the other it's logical, it refers back to the one before." (M16C, 45-54)

As before, some answered the question rather than assessing its understandability, but answers indicated understanding:

"I have told you where I get it!" (F6P, 65-74)

"Left side." (M6P, 55-64)

"Well, here [gestures to centre of chest]." (F17E, 45-54)

In a few Pakistani interviews, the project worker probed whether or not the responses (right: left) were understandable, and the participants all agreed that they were.

### English

All English speakers said they understood the question.

### Summary of findings relating to RAQ 1h

Whilst most participants from all groups said they understood the question, some Chinese participants appeared confused and others made a suggestion to improve question wording.

## **6.2.9 RAQ 1i: Do you get it anywhere else?**

### Cantonese

The Chinese project workers' English translation of this question was: "Do you feel pain also in other parts of your body?" This question was understandable and acceptable overall to the Cantonese speaking people interviewed. Again, most participants said that they understood this question, and some answered the question in a way that showed understanding. However a couple of participants said that they understood but their answers revealed that they related the question to non-cardiac pain:

"Oh, the arthritis, I have it elsewhere." (M12C, 75 and over)

"It travels, stomach pain, sometimes you get headaches." (F13C, 75 and over)

One participant, who had had previous difficulty in understanding and concentrating on the exercise, said

"I don't know." (F16C, 75 and over)

Another participant responded just by shaking his head, and it was unclear if he was answering the question, indicating he didn't understand the question, or was unable to engage further with the task (M10C, 65-74). A few participants suggested a better way of saying the question:

"Say, apart from X...is there anywhere else?" (F3C, 65-74)

"It should be the other way round [Does any other part feel the pain?]."  
(M14C, 45-54)

### Punjabi

This question did not feature in the Punjabi version of the RAQ used by the Newcastle Heart Project.

### English

This question was queried only briefly in English speakers, who thought it was easily understandable, often nodding or quickly responding:

"Och yes, yes." (M26E, 65-74)

### Summary of findings relating to RAQ 1i

This question was not equivalent across language groups. It was not present in the Punjabi version, and whilst English speakers understood the question, some

Cantonese speakers were confused by the question and related it to non-cardiac types of pain.

**6.2.10 RAQ 1j: Did you see a doctor because of this pain? What did he say it was?**

Cantonese

All Cantonese participants understood the words in this question, a few answering it directly:

"Of course!" (M6C, 65-74)

However, not all participants understood the intent of the question or the fact that it was referring to the pain and discomfort in the chest:

"It depends what it is. Sometimes I would go to a doctor and sometimes I wouldn't." (F13C, 75 and over)

"If you're in pain you have to see the doctor." (M3C, 75 and over)

Some participants' responses showed their attention was wandering at this stage of the questionnaire.

Punjabi and English

This question did not feature in the Punjabi version of the RAQ and the English speakers interviewed were not asked if they understood it, it not being central to the Rose Angina Questionnaire.

### Summary of findings relating to RAQ 1j

Whilst it is not possible to assess equivalence of meaning of this question across groups, as Punjabi and English versions were not probed, the item was misinterpreted by some Cantonese-speaking participants, who were unable to relate the 'pain' in the question to the 'pain or discomfort in the chest' at the beginning of the questionnaire.

#### **6.2.11 RAQ 2a: *Have you ever had a severe pain across the front of your chest lasting for half an hour or more?***

##### Cantonese

The majority of Cantonese participants, men and women, responded that they understood this question and that half an hour was thirty minutes. When project workers queried what participants thought the question was asking about, some participants were able to associate the question with cardiac pain or, correctly, myocardial infarction:

"You're asking me if I had serious chest pain...I don't know...maybe the heart." (F1C, 55-64)

"Heart attack." (M12C, 75 and over)

However, one participant answered the question in a manner that indicated she had not interpreted the question as pertaining to cardiac pain:

"It doesn't last for long. If I get the unhappiness, the *ny ju* feeling, it only lasts a short while." (F13C, 75 and over)

When asked what she thought the question was about, the participant above answered:

"Psychological pain." (F13C, 75 and over)

There was also some confusion around the task. For example, the following participant said she understood but seemed not to relate the question specifically to chest pain:

"It's a good question, asking you about the state of your health. It's about general health. Will they be helping us?" (F3C, 65-74)

In two cases the meaning of the phrase 'severe pain' was probed, and those participants responding agreed that it meant very painful, very severe (F1C, 55-64) or very serious (F5C, 45-54). No Cantonese women suggested alternative or better ways of expressing the question, but a couple of the men were able to do so:

"The term pain in the chest is too general. It's better to specify, say it's related to the heart, there's different organs involved." (M16C, 45-54)

The project workers and a couple of the more literate participants thought the translation could be improved:

"It could be made better to show the level of language...if the questionnaire is being filled in, it will be different from being asked. I feel this is a translation of an English version". (M4C, 65-74)

### Punjabi

Some of the Pakistani women interpreted the question differently than other participants. Whilst some participants said the question was understandable, others expressed problems with the translation of 'the front of your chest', *morla/ mohray*, for example:

"*Mohray* is not very understandable for most Pakistanis." (F3P, 55-64)

"*Morla* is not the right word." (F16P, 55-64)



The reason for this was that, as with the term *padhry* mentioned above, *morla* was seen to be a very pure Punjabi word used in the country near the Indian/ Sikh part of the Punjab:

"That is for outside people, not for city people. This word is mainly used for people from villages." (F6P, 65-74)

"That's Sikh Punjabi." (F11P, 55-64)

Several participants were in agreement in suggesting an alternative word that would be understood by Pakistani Punjabi speakers:

"*Agla* is [gestured to front of chest]." (F6P, 65-74)

"*Agla*. All Punjabis would understand it. The word should be *agla* and not *morla*." (F11P, 55-64)

However, one participant suggested a different alternative:

"You could use *samney* instead of *mohray*." (F3P, 55-64)

Most Pakistani men appeared to have no objection to the phrase *morla* for front of chest. The translation for 'front of chest' was not probed specifically by the project worker, excepting two cases, when participants agreed it was the chest area:

"[Front of chest] is 'chest', *chatti*." (M14P, 65-74)

The second problem with the interpretation of this question by the Pakistani women was that two participants (F12P, 45-54; F9P, 55-64) interpreted the phrase 'front of chest' to be 'nipples', still believing the word *chatti* to refer to their breasts:

"When you're saying front of chest, you're talking about nipples, and when you say *chatti*, you're talking about breasts." (F9P, 55-64)

There was some confusion in both men and women about the interpretation of the term 'severe pain'. Despite the Punjabi translation, which was *sakht dard*, the two original project workers had misunderstood the necessity to strictly adhere to pre-existing translations, and re-translated the question using the Urdu phrase *shadeed dard*. Hence participants were describing what they understand by *shadeed*, not *sakht*, and so the true task was undermined. The following are examples of comments made:

"Some people won't understand *shadeed*, it is an Urdu word. A different way of saying it would be by *both zyada* (too much)." (F4P, 55-64).

"*Shadeed* is not a Punjabi word. In Punjabi you say *both zyada*." (M14P, 65-74).

Most of the men probed did, however, understand the Urdu word *shadeed*, for example:

"...too much pain (*zyada takleef*)."

In some instances the participants actually used the Punjabi term as found in the RAQ translation:

"[It's] *sakht dard* (severe pain)." (M8P, 55-64)

"'Sharp' pain or *sakht*." (M14P, 65-74)

In one instance, the third project worker employed did probe the meaning of the Punjabi word for severe that was used in the RAQ, *sakht*, which met with understanding:

"It means a lot, it means worse." (F18P, 45-54)

Some Pakistani participants interpreted this question as relating to cardiac pain or a heart attack:

"I think they want to find out about 'angina'. It could be 'muscular pain' as well." (F16P, 55-64).

"Heart attack'. The sign is that I'm going to have a heart attack. Or the second thing is that my veins are narrowing and I'm going to have 'angina'." (M12P, 75 and over)

However, in the case of one Pakistani participant (M16P, 55-64) it became apparent through the translation and discussion session with two project workers present, that the project worker carrying out the interview had actually prompted this answer, contrary to his training:

Project worker #2: [Project worker #1] had to say, 'You think it might be heart attack?' And then [the participant] said, 'Oh yes, this is what you asked.'

Other Pakistani participants, however, did not relate this question to a heart attack, or indeed to any cardiac event, interpreting it rather as pertaining to a range of other health issues:

"I thought you were asking me about "asthma" " (F5P, 45-54)

"That you are *bumar* (ill), that you have an illness (*bumari*). " (M7P, 45-54)

One participant was unable to provide a response when asked why the interviewer would ask her this question, but was able to imagine why a doctor would ask her:

"Maybe the doctor would be asking if there was a 'heart problem'." (F18P, 45-54)

## English

All the English speakers either responded that they understood the question, or more commonly answered it directly. Most participants did relate the question to the heart or, more specifically, to a heart attack:

"I would think you were probably wondering if there was a heart problem."  
(F4E, 65-74)

"Well I would imagine that that is the warning of a heart attack." (M11E, 75 and over)

## Summary of findings relating to RAQ 2a

This question was not found to be equivalent across the groups studied. Whilst English speakers understood the question, most Cantonese speakers understood the words but some appeared confused about its meaning and a couple thought the translation was an awkward direct translation from the English. There were also differences in interpretation in the Punjabi-speaking group. First, the term 'front of chest' had been translated into the form of Punjabi spoken by villagers near the border between India and Pakistan, and was not understandable by some of the Pakistani people interviewed. Participants agreed on an alternative, *agla*, that would be more easily understood by the Pakistani Punjabi-speakers. Second, some Pakistani women continued to misinterpret the questionnaire as relating to their breasts, and hence interpreted 'front of chest' to refer their nipples. Some participants from all groups were able to relate this question to a cardiac pain or myocardial infarction, although some of the ethnic minority participants mentioned other non-cardiac conditions.

### **6.2.12 RAQ 2b: *Did you talk to a doctor about it?***

The translation of this question was probed only in the Punjabi-speaking group. All participants said they understood the question and found it acceptable.

## **6.3 Chapter summary**

A number of problems were found with the Punjabi and Cantonese versions of the RAQ that undermine its equivalence when used to compare data from Punjabi, Cantonese and English-speaking groups. For example, the translation for 'chest' was interpreted by some Pakistani and fewer Chinese women to mean 'breasts'. 'Walking uphill' was translated in Chinese as 'walking the slope', without stipulation of the direction, so that some Cantonese speakers interpreted the question as pertaining to walking downhill. Many Chinese interpreted RAQ items to be referring to breathlessness rather than chest pain due to ambiguous wording, and an additional question was present in the Chinese version that was not present in the English or Punjabi versions. In addition, there were also individual differences across all groups in the interpretation of questionnaire items and phrases. These findings, and their implications for distorting angina prevalence, are discussed further in chapter 8.4. Where translations were inappropriate, alternatives were suggested by participants. A number of methodological insights were gained into carrying out this type of lay assessment task by proxy. For example, as shown in these results, the extent and nature of project workers' questioning varied considerably between groups and individuals. In addition, participants varied in their understanding of the nature of this task, and some found the task confusing. These findings will also be

discussed in depth in chapter 8.2.2.4. The next chapter, chapter 7, presents interview findings pertaining to response tendencies which may effect RAQ response.

## **Chapter 7**

# **Factors relating to questionnaire response tendencies**

## **7.1 Introduction**

In Chapters 5 and 6, results pertaining to the cultural and linguistic appropriateness of the RAQ were presented. In addition to conceptual relevance and lexical equivalence, another component of cross-cultural validity concerns general response tendencies. For example, familiarity with a questionnaire task may determine ease of interpretation and response; cultural norms may govern attitudes to research and to disclosure; and the degree of deference to, satisfaction with, and tendency to consult the medical or health care professions may affect an individual's response. This final results chapter presents findings that relate to general questionnaire response tendencies within each language group that may influence the way an individual perceives and responds to a health-related questionnaire. In section 7.2, experiences of, and attitudes to, questionnaires are explored. In section 7.3, views on, and experiences of, health care and the medical profession are presented. In section 7.4, attitudes to taking part in research are examined; in addition, understanding of, and motivations for, participating in this research study are presented. The effect of these findings on the feasibility of using the RAQ in a cross-cultural context is discussed in Chapter 8.5.

## **7.2 Experiences of, and attitudes to, questionnaires**

Participants were asked if they had ever received a questionnaire about their health. Only a minority in any group remembered taking part in any previous health surveys requiring questionnaires. Many participants had never answered questionnaires about their health:

"I never filled in a questionnaire about health." (M2C, 65-74)



"We never get them." (F9P, 55-64)

"No I can't remember actually." (M15E, 65-74)

Participants who had filled out a questionnaire about their health had usually done so as part of a job or insurance application process rather than a health-related survey.

Only the English-speaking participants mentioned these types of questionnaires:

"When I apply for jobs and things like that and when I worked in finances we had to fill out a health form quite regularly." (F17E, 45-54)

"Yes, I think so- well when the heart thing arose of course, the insurance companies were interested, the car insurance." (M11E, 75 and over)

A minority of participants did mention taking part in questionnaire-based health surveys or clinical research:

"We got a letter, I think it was from Aberdeen University, or Aberdeen health board about some questionnaire I'd filled in when I was 11- they'd done some survey and they were following people... they were following everyone up who had filled this in, to find out what their health was like, and everything." (F2E, 45-54)

"Yes...I did one recently, I actually took part in a clinical trial for cholesterol." (M17E, 45-54)

"I was asked to take part in [medical research] by the University." (M14C, 45-54)

When mentioning the type of questionnaires they had filled out in the past, most other participants mentioned consumer or attitude questionnaires rather than surveys specifically focused on health:

"Well I suppose sometimes you get these shopping surveys and there's a health section, how many times do you take aspirin...I'm not really aware of anything." (F13E, 45-54)

Participants often had a negative attitude towards this type of postal questionnaire:

"The majority I wouldn't fill in, because they are market research." (F5C, 45-51)

"Normally I throw them out. Sometimes I fill them in but normally I feel this is rubbish." (F16P, 55-64)

"There's always those shopper surveys, they go straight in the bin [laughs]...I wouldn't bother with it at all." (F5E, 45-54)

In contrast, a few English-speaking participants said that they were willing to respond to postal questionnaires related to consumer surveys:

"I fill out surveys. Sometimes it says you're going to win some money if you reply, but I think on the whole it's really just, if my likes and dislikes can influence something, especially you know supermarket's products and things, if what I put down can influence what they're going to stock, then why not?" (F12E, 45-54)

"This last year, I've probably filled out 6 questionnaires...[they've] come through the post... They are mainly about... your shopping habits...I send them back. If it'll help." (F25E, 55-64)

A couple of English speaking participants expressed their opinions about how questionnaires are designed:

"Some of their questions are just totally irrelevant and stupid...it's because they assume things. I tend to answer a lot of questionnaires, some of them are actually put together quite well, some of them I can't quite work out what they're trying to, what their goal is." (M16E, 45-54)

"I prefer something like this [face-to-face interview], rather than filling in a form...what in hell do they mean by this, you know, put a tick on this, is it good or very bad, how good is good- it's a bit too imprecise...I would certainly rather you looking at me and asking me, because if I didn't understand what you said hopefully I'd have the nouse to come back at you and say, 'What do you mean?' Some people are troubled by a sheet of paper, or blank boxes, you know, to fill in...I think sometimes it's too open-ended." (M27E, 45-54)

Participants were asked whether they would respond positively to receiving a health-related questionnaire or request to take part in a survey. Overall, the attitude to health-related questionnaires was positive:

"It's good to answer. I've had 2 or 3, and I've always filled them out and sent them. If someone is doing research, if they want my help then I will if I can" (F3P, 55-64)

"You should participate." (M9P, 55-64)

"Also being of a medical research background you know I don't mind people, I don't refuse to do surveys and things like that. I know it's valuable, you know." (F13E, 45-54)

In addition, participants cited a number of factors that would influence whether or not they responded to a questionnaire or took part in a survey. For example, participants said they would consider the source of the questionnaire:

"It would depend where it came from- if it was like Lothian Health- I would maybe even phone up and check that it did come from them." (F17E, 45-54)

"It depends where it comes from. Any questionnaire I wouldn't fill in if I was unsure of the origin, if I was unsure what it was going to be used for. If I didn't have confidence in the people who were sending it out, I'd just bin it." (M1E, 55-64)

A couple of the ethnic minority participants specifically articulated the wariness of taking part in something without personal endorsement by a recognisable community member:

"I don't have confidence about these surveys...you physically are here, and I have confidence in you." (F14C, 55-64)

"If I didn't know the person...if it wasn't you that came today, I would have said no. You already know a lot about me." (F3C, 65-74)

The relevance and purpose of the questionnaire was also a factor that influenced participants' perception of and response to the survey:

"It would depend on the purpose, you know if it was obviously something commercial, you know if it was a drug company or something like that, then I wouldn't bother- they were just trying to maximise their profits or something like that- but something like what you're doing, I wouldn't mind helping, where it's something that's going to be of benefit to patients and doctors and improve things, hopefully." (F5E, 45-54)

"You should know who is asking the questions. Why are they doing it? Are they going to find resolutions, are they going to tell how to improve things?" (F4P, 55-64)

"I'll see if it's related to me or if I'm interested- if not, I'll dump it, but definitely I'll read it before I decide." (F7C, 65-74)

Amongst the Cantonese participants, literacy in both Chinese and English was identified as a factor that would influence response. Many of the participants who were living in sheltered accommodation were illiterate and would automatically take any correspondence to the Cantonese-speaking warden. Others relied on family members or on Chinese community support groups to read correspondence:

"All my letters I take to [community group]. How could I fill them out, I'm illiterate. There was no education in the past." (F15C, 75 and over)

"I know Chinese but I'm not very confident so I'd have to get an honest person, someone I know and trust, to fill them out for me." (F16C, 75 and over)

"Any correspondence I ask the warden to look at. I maybe have received questionnaires about health but if they're in English the warden explains them briefly and very often I just dump them in the bin." (M5C, 65-74)

Even though some participants could read and write Chinese, none were proficient enough in English to read an English letter coming through the post or fill out a questionnaire in English.

"If it comes through the post, I am happy to fill it in but only if it is in Chinese. If it was in English I'd have to ask my husband or daughter." (F9C, 45-54)

"It depends on the language...if it's English I would throw it away, if it's Chinese I would have a look." (F1C, 55-64)

"If it's in Chinese I'd definitely have a look, for English I'd just glance through it to see if I could understand. Normally I'd have to answer in English, so no [I wouldn't respond]...if it's in Chinese I'd definitely read it." (M1C, 45-54)

Two of the Pakistani women also mentioned that their children would fill out questionnaires for them.

The following participants said that they would probably not respond to a health questionnaire:

"You get so much junk mail so you'd think that was junk mail as well. I couldn't promise I'd go through it." (M2P, 45-54)

"It doesn't matter which language it comes to me or anyone else, nobody bothers with it. They pick it up and throw it away." (M14P, 65-74)

Whilst this participant felt his illnesses were not sufficiently important to do so:

"I have never had [a questionnaire] and I would not fill it out because I have 'normal' *bumary* (illness), it's not 'dangerous'. It's embarrassing to some people." (M5P, 45-54)

A few of the ethnic minority participants interviewed expressed doubts that they would understand the questionnaire unaided:

"Yes, the questions that I can understand I will answer if it is within my 'qualification' to do so." (M1P, 40-54)

"I could do it with the help of an educated person- I don't understand it [questionnaires]. I will be happy to fill it out." (F8P, 55-64)

"I'll have a look, but whether I'll digest them, or really know what they're talking about, is another matter. Sometimes I don't understand." (F8C, 55-64)

"I wouldn't know how to fill it in." (M10C, 65-74)

### Summary of experience of, and attitudes to, questionnaires

All three groups expressed a range of opinions about questionnaires. Participants from all groups said they would consider the source and outcome of a questionnaire before filling it in, but overall expressed a positive view towards taking part in non-invasive health-related research. However, some ethnic minority participants felt they would be insufficiently educated or knowledgeable about the questionnaire content to answer. In addition, the majority of the Chinese participants felt that their illiteracy in both English and Chinese scripts might be a barrier to responding to a postal questionnaire or request.

### **7.3 Experience of, and attitudes to, health care**

Participants from all groups recounted experiences of primary and secondary care, and most engaged readily with the medical profession when ill:

"With health, you just have to be careful and if you're ill, go and see a doctor otherwise your time's up." (M6C, 65-74)

"If there is any problem or I have any concern about my health I can go to the doctor." (M11P, 75 and over)

"When it's necessary, yes, and I'm not postponing anything, and if I have a twinge or pain I seek medical advice." (M7E, 55-64)

However, some participants expressed a reluctance to go to their GP unless they perceived their condition to be serious, due to a wish not to bother the doctor with a minor complaint:

"I don't like going to the doctor. I put up with small problems. I go when I have a main problem. I don't like going to the doctor very much, that I should give him trouble going again and again." (F2P, 45-54)

"If it's something that you know will pass or that you can treat in some way yourself, quite simply, I don't see the point in clogging up the doctor's surgery...I mean if I had a sudden onset of something inexplicable, then I would go to the doctor." (F5E, 45-54)

"I think I'd really need to feel ill. I wouldn't go for a sniffle, or a cold or a flu, or just anything. It would need to get really painful, to I thought it was serious before I'd go, there's no use in trifling the doctors, you just waste their time." (M3E, 45-54)

Others would wait to see if the condition cleared up by itself:

"I'll go to the doctors if I need to, but I just don't go right away, I'll just hope that whatever it is going to clear up." (F7E, 75 and over)

"Very rarely have I seen a doctor...not because I know I'm going to get a bad service, but just generally, it'll go away." (M17E, 45-54)

One Cantonese woman expressed the view that Chinese women were less likely to attend screening clinics:

"A lot of the women in the Chinese community about my age don't go to well women's clinics...Chinese women are more conservative, old-fashioned thinking, and less educated...I mean why would you go to the doctor if you weren't ill...but then by the time you go to the doctor it can be too late." (F6C, 55-64)

Another participant expressed a sense of the futility of seeking medical help in old age. When asked if he thought he should go and see his GP about a number of 'attacks' he'd experienced, he replied:

"No, why should I? I'm 77." (M12P, 75 and over)

Only one of the women interviewed, a Pakistani participant, mentioned the preference for a female doctor:



"If it's a male doctor then it's going to be more *takleef* (discomfort) for me, I'd prefer to see a 'lady doctor' [about piles]." (F2P, 45-54)

In terms of regularity of consultation, many people were unable to assess whether or not they went to the doctor more or less than other people their age, pointing out that:

"I don't know about other people, how often they go to the doctor." (F1C, 55-64)

Others, particularly if they had suffered bad health, said they went to the doctor more often than others did:

"I think I do go to the GP more often than other people, because I am generally unwell." (F3C, 65-74)

Of those that consulted their GP more often than others did, some cited a particular major health problem or ongoing general ill health as the reason they consulted their GP more regularly, although some hinted at an increased willingness to present with any health problem:

"Oh, definitely more. Whenever I have a problem, I'll seek help from the doctor. Also because I have a heart problem I have a check up every 3 weeks, so I think I see the doctor more." (M16C, 45-54)

However, most participants rated their frequency of consultation as less, largely due to not having any major health problems:

"I've been here nearly 20 years and I seldom consult my GP." (F10C, 45-54)

"I count myself as very healthy, I didn't really see doctors very often, not very often at all." (F4E, 65-74)

Many participants spoke positively about their doctors and appeared satisfied with their treatment. All three groups seemed to value a doctor that listened well, and



gave a sense of personal respect and care to their patient, as well as having good medical knowledge and abilities.

"Overall I'm quite happy, my own GP is a good match, he's attentive, no discrimination." (F8C, 55-64)

"When I go to the doctor I am looked after- he speaks to me with *pyar* (love). He listens, he gives me *hosalah* (encouragement, patience), he helps me to be patient, he gives me full 'treatment'. I am 'happy'. He knows about my illnesses." (M5P, 45-54)

"I've never had a bad experience. I've felt that all the doctors that I've had over my lifetime have been good, caring people." (F12E, 45-54)

The English participants were asked what they thought were the qualities of a good doctor, and, echoing the sentiments above, the majority responded that the doctor's listening skills and concern was most important:

"Someone that listens to you, I think and doesn't just, oh, yes a prescription, someone who shows you a little bit of concern I think." (F13E, 45-54)

"I suppose what you really want from your doctor is a caring one." (M3E, 45-54)

Other participants reported that the doctor's potency in treatment was low, but didn't seem to blame the doctors for this:

"My doctor has done a lot- he's given me lots of different new types of medicine. It's not the doctor's fault- he's human, he's done his best." (F5P, 45-54)

Some participants did, however, express dissatisfaction with their doctors. This was seen to be due to the lack of time invested, and lack of personal care from the GP that those above said they valued:

"On the whole I'm satisfied, but there's some minor issues. For example if I want to ask a question, the doctor is in a hurry to see other patients. It seems to me that the doctor is not really keen to answer the questions." (F7C, 65-74)

"Well, I remember going once about migraines which were pretty horrendous at the time...and the doctor more or less kept looking at his watch all the time, and I was very upset about that because I thought, he's only thinking it's a headache, and it's not." (F25E, 55-64)

"My general opinion is that doctors don't have time. They give appointments after 1 or 2 months. They give you medicine. They don't 'care'. He'll speak to me for 3 or 4 minutes, he'll ask, What is your *takleef*? I'll tell him and he will write a prescription then send you away." (M8P, 55-64)

"I do not get *aram* (comfort/ better) so obviously I am not happy with the doctor. The service the doctors give is good but the medicines don't work." (M9P, 55-64)

Some Pakistani men were particularly frustrated at being prescribed painkillers when they felt their condition warranted more:

"I have explained to the doctors, but they're not interested...I am not happy with the attitude of doctors- they just tell me to take 'painkillers'. I have given it up completely. I have no faith in doctors. Eventually you give up when there's not hope left when you've tried everything...if you go to the doctor you should be cured and shouldn't have to go again and again. I don't go any more... You don't expect me to talk to the walls? I am in this country for the past 1 ½ years, by now he should have sent me to a specialist for a solution to my problem... We are Pakistani and that might be the reason we are not being properly looked after." (M1P, 40-54)

"I go when I have a big problem. Despite the big 'problem' they give me paracetamol. For nosebleed, they gave me medicine that was not effective. I said to the doctor, 'If you cannot cure me, I will get 'private' help. I can't sleep at night and you give me paracetamol for it.'" (M13P, 45-54)

"It's a waste of time going to the doctor as they'll give you paracetamol, which you can self-prescribe. I'll only go after taking paracetamol- my conscience will force me to go to the doctor." (M2P, 45-54)

There were conflicting opinions on hospital care:

"Oh yes, I'm quite satisfied. I had to stay in hospital for 5 weeks and the nurses were very good and tried to encourage me to take more nutritious food." (F12C, 65-74)

"I hurt my head in the shop and I went to hospital and they didn't let me eat anything until the next morning and then the scan was done the next evening. They treat you like animals." (M13P, 45-54)

"When I was in hospital the nurse wouldn't speak to me, avoided me, and there was nothing for me to eat." (M6C, 65-74)

In addition, others were frustrated with the long waiting lists after being referred to secondary care:

"I have a complaint...I waited six months for a hospital appointment- in 6 months it could be unbearable." (F2P, 45-54)

"I waited one year for a psychologist appointment. They put me in a 'self help group'. I was very disappointed. I never thought that after one year they would tell me to do that. I didn't think it was helping me. They didn't give me advice." (F3P, 55-64)

"My family's care is not good. My wife has a stone in the kidney and it has taken 2 years for the appointment with the specialist. They 'ignored' me. As far as I know, the communication is fine- my daughter goes to the doctor with my wife. The care system is good but there is always a 'delay'. It might be because we're Asian." (M7P, 45-54)

"Now there were about 60 people there [in the hospital waiting room]...you don't give appointments to 60 people, you know. [I waited] two hours...It's some time for any civilized appointment system." (M5E, 75 and over)

Another theme that emerged from the non-English speaking participants was that language could be a barrier to effective communication:

"It's very difficult to describe pain to a doctor, even with an interpreter to describe the kind of pain. Sometimes I have pain when I'm breathing and it's very difficult to describe. I find it very difficult to express myself to a GP even with an interpreter." (F8C, 55-64)

"[The care] is *ma fu* (not very detailed, doctor not putting in enough effort). [I'd like the doctor] to be a bit more detailed when he asks questions but because I need an interpreter it's a bother and I try not to trouble other people." (M5C, 65-74)

"I don't understand what he is saying, there should be a Punjabi translator." (M8P, 55-64)

"The majority of people have language problems and can't communicate properly and they're left behind. Interpretation services [are a solution]. Also more 'Asian doctors' in surgeries; and there should be staff in the surgery who know how to speak Pakistani and Urdu." (M6P, 55-64)

Participants mentioned bringing a family member fluent in English to the consultation with them:

"My daughter goes to the doctor with me. Because I don't understand what they say." (M15P, 65-74)

"If there is any problem I don't speak English very well so I always take someone with me." (M11P, 75 and over)

"My children go with me, or [council interpreter]. Since I moved, it's most often [another sessional interpreter]." (F12C, 65-74)

In contrast, a few participants stated there was no major communication problem due to speaking adequate English themselves:

"I always go alone. I can explain very well according to my English and he always understands. I never ask them to bring an 'interpreter'. I get along with my *tuti puti* English (bits and pieces, broken English)." (M12P, 75 and over)

"I used to go to English classes 2 evenings a week. So I learnt a little bit of English and this makes me capable of explaining myself." (M14P, 65-74)

Some participants were reluctant to blame individual doctors for perceived problems with care, but instead saw faults in the system. This theme was particularly strong amongst the English-speaking participants.

"Recently the care I've received from the hospital was not very good- I wouldn't 'complain', probably it's due to the economy, staff shortages etc." (F5C, 45-54)

"They want to save money for the government. Twenty years ago there was care but not now." (M7P, 54-54)

"I've not really had any problems myself but one thing I think I am aware of is that I think the health service has deteriorated very much in the last few years." (F2E, 45-54)

"I think that, knowing what it used to be like, you have to come to terms with the fact that it's different. I don't blame the practice for this, I blame the whole situation and the way it's run, that's the problem, the NHS." (M11E, 75 and over)

Some of the Cantonese and Punjabi participants were appreciative of the fact that medical care in the UK was free at the point of delivery:

"In this country, you can't complain. I have to be thankful, as you do spend more abroad on insurance and health costs. I'm not going to go there either." (M2P, 45-54)

"[The health care I've received is] very good. Here you don't pay- what more can you ask for?" (M16C, 45-54)

When describing his hospital stay in China, another participant mentioned that medical care there could be extremely expensive:

"If you don't have money [in China], forget about it. I attended the 3 biggest hospitals in Canton. It cost about 100 odd coupons a day, equivalent to about 300 Hong Kong dollars." (M6C, 65-74)

Only one participant was critical of the whole system here in comparison to her country of origin:

"I think they don't understand us very well, us Chinese people. They just treat everything as not very serious, as minor trouble. In Hong Kong at least I can explain things in detail, all I can do here is point out the pain, I can't explain any more about it. The standard of doctors here is not very good, probably." (F9C, 45-54)

Some participants from all groups spoke about using alternatives to mainstream medicine. For example, several Chinese participants spoke about their use of a bonesetter, often whilst living in Hong Kong:

"When I was younger I did kung fu and the kneeling was on hard floors and that caused problems in my knee and my master used herbal treatment and *te ta* (bonesetters)." (M6C, 65-74)

"I crushed my chest against the wheel. I consulted a bonesetter. I saw a Western doctor, but I also consulted a Chinese doctor." (M4C, 65-74)

"[Pain in back, buttocks]. Someone else recommended an experienced bonesetter, with patience to try to find out the cause of my illness...During the 9 months treatment the bonesetter would sometimes give me herbal drinks to get rid of the kidney and liver fire. Also the bonesetter massaged my kneecap etc subtly so after 9 months the problem was cut, *sung sai tung* (relaxed, relieved, no pain)...there's still a bit of pain but the bonesetter said just to continue with a bit of massage so I go to a Chinese masseuse. Western physiotherapy didn't work." (M15C, 55-64)

In contrast, another participant had turned to Western medicine when Chinese herbal medicine had not been effective in curing him:

"I had pain in my thigh, pain in the bone. I consulted a Chinese herbal doctor who gave me poultices etc but it didn't work so we went to see the Western doctor and I had an injection every day for a month...since then I've been cured." (M14C, 45-54)

A couple of the Pakistani participants mentioned being treated by non-Western doctors; F9P had been treated in Pakistan for pain in her kidneys by a *hakim*, a traditional doctor:

"I was treated by a *hakim- desi* (mother country/ traditional) *diwhi* (medicine)...He gave me tablets and injections as well." (F9P, 55-64)

"I had injections, I went to 'hospital' and had injections round my navel. I went to a person who sucked the poison with his mouth and died." (M13P, 45-54)

A number of English-speaking participants had also tried alternative or complementary therapies such as chiropractors, acupuncture, hypnosis, and herbalism after the failure of mainstream medical care, for example:



"I also feel that chiropractitioners should really be taken more into the health service...Because it doesn't just help the pain in your back, it helps your whole health." (F10E, 55-64)

"I had two lots of physiotherapy, and I had acupuncture...that was smashing, really good...[the physiotherapy] wasn't really [effective]... that's why I got the acupuncture, and it was fine after, what a difference, even after a few sessions." (F17E, 45-54)

A theme present only in the English-speaking group was that of long involvement with a general practice:

"We've used the same practice for 50 odd years now and that's Dr M, indeed, it was his grandfather and his grandfather's partner, Dr B who was the doctor at that time." (M11E, 75 and over)

"The surgery has done a great deal for us, and as I say, the least we can do is do something for them. I mean after all, our first doctor was Dr M and he had a son and daughter, and our second doctor was his daughter." (M13E, 75 and over)

"I knew his [GP's] father, he was my doctor before Dr A, and his grandfather-when I came to Edinburgh it was his grandfather in the practice. And an auntie as well. I've definitely no complaints about doctors." (M14E, 65-74)

### Summary of experience of, and attitudes to, health care

Participants expressed a range of satisfaction with the health services; whilst some were dissatisfied with the care they had received, many participants from all groups felt that they had received adequate medical care. No dominant culture-specific themes emerged, regarding dissatisfaction or suspicion of the medical profession, which could influence reporting of symptoms and RAQ response; however, a small number of participants from ethnic minority groups indicated a perception of some racial discrimination. Individual differences in perception of the severity of symptoms and the responsiveness of health care professionals may be more likely to influence RAQ response. Participants from all groups spoke of their doctors and

health care professionals in a similar range of ways, the majority having respect for their doctors, although there were some examples of the language barrier being a frustration to the Punjabi or Cantonese participants. Particular deference to the health care profession did not emerge as a dominant theme in any one group.

#### **7.4 Attitudes to taking part in research**

The most dominant theme to emerge as to why people participated in this particular research project was that of altruism: the wish to help others and to benefit medical research:

"I know that it will be put to good use, and help some patients in the future." (F13E, 45-54)

"To help, if I thought...the research would help somebody else... if I can help, if any day it helps one person then we win... You know society itself has got to progress I mean you can only progress by you know, communicating and helping." (M17E, 45-54)

"Through this process, it's not beneficial to the interviewer or the interviewee, but it's good for everyone in the community so one shouldn't be selfish. Also it's good for the medical research, to make it perfect." (M14C, 45-54)

"This means you learn things for someone in the future." (F7P, 65-74)

A theme that strongly emerged from the Punjabi-speakers interviewed was the desire to help their own community. Participants saw the research as raising awareness of health within the community, and raising general awareness of the community's issues:

"I'm very glad someone has come forward to talk about it in the community...the research is going to be beneficial to the new generation and for the whole 'community'." (M2P, 45-54)



"Because I thought the research would give us a solution to our problems. You should "show" what your *bumari* (illness) is, not 'cover' it." (M5P, 45-54)

"It's better for us to tell you about our problems. Some people are not happy with the treatment they are receiving from the doctor, so by telling you we can expect some help from you. It's a very good cause and the community will benefit from it." (M10P, 55-64)

"It could be beneficial to us...our people experience a lot of problems in hospitals and stuff, and that's what these people are going to find out, how will they find out if we don't talk about it?" (F12P, 45-54)

"It's a good thing that you're doing this and through you we can explain our problems." (F2P, 45-54)

"It could be best for me and for my other brothers and sisters as well because when they do these projects they do them for our good." (F18P, 45-54)

Only a couple of Cantonese participants specifically mentioned the Chinese community as benefiting from the research:

"If it's helping the elderly, and also the Chinese, I should [take part in research], so it's doing some good to others." (M5C, 65-74)

"I wanted to feed back the information to the GP, for example about antibiotics, and express my opinion. Basically to express views about medication etc, and I want to help the ethnic minority community to help them have better health. I read about antibiotics, but not everyone knows that." (F1C, 55-64)

Amongst some of Cantonese and Punjabi-speaking participants, there was some misunderstanding about the consequences of participating in the project. For example, some participants thought that the interview would provide a means of helping them with their own health problems:

"[The doctors] are not interested so I'm very happy someone's come forward." (M1P, 40-54)

"I thought that it is going to be beneficial to me. I am very happy you have come here, I will tell other people as well that someone talked to me about

my problem. I am very grateful that you have contacted me." (M12P, 75 and over)

"Because I was in pain...if I can get out of this, [help for] my stomach problem." (F15P, 55-64)

"I'm not well, I have a lot of illness...I want people to help me." (F3C, 65-74)

"Also in future it will be easier to ask for help if I have already given help." (M11C, 65-74)

Some of the ethnic minority participants stated that the reason they had participated because a social contact had asked them to do so.

"Because my daughter told me you were going to do this interview and there is no difference between my daughter and you, so I told her, let her come." (F17P, 75 and over)

"Because of you! [to project worker]. If it was not you, if it was a stranger, I may not have been willing to participate. Because I know you. If it was somebody else, it would depend- if it was worthwhile to the community I might still take part." (M16C, 45-54)

In contrast, the English participants were recruited largely via their GP, and a couple of participants viewed taking part as a reciprocation of the care they had received from their doctors:

"Well, as I say, the...surgery has done a great deal for us, and as I say, the least we can do is do something for them." (M13E, 75 and over)

"It's a way of saying thank you. There's quality in my life because of the medical treatment I got so if there's some way I can say thank you then I'll do it." (M7E, 55-64)

A few Cantonese participants also thought that the interview was a means of increasing their own knowledge:

"Because I want to know more about illnesses myself." (M7C, 65-74)

Others expressed the view that they thought their own experience of pain and ill health was relevant, which prompted them to volunteer:

"There was a talk saying it was about pain and ill-health and I said, that's me!" (M6C, 65-74)

A minority of English and Cantonese speaking participants had taken part as they had viewed the interview as an interesting diversion:

"Well, I thought it might be a little bit stimulating, you know [laughs]. You need a few things like this, so long as you didn't ask me to take medicine!" (F15E, 75 and over)

"I have nothing to do, my husband and I are in [residence] all day." (F12C, 65-74)

Some English-speaking participants expressed reluctance to take part in any research that was medically intrusive:

"I wouldn't be happy to take part in anything that I thought was personally intrusive. Also, if it involved us in any hassle, then I would have to say no." (F2E, 45-54)

"I wouldn't like to take one where I'd have to take medicine. Because my neighbour upstairs, she's diabetic, and she's just had a scare actually. Mind you, they were quick in picking it up. But what she was taking, they asked her, like you've asked me, was she prepared to, and she did gladly do it, but the tablets she was taking, they had a dreadful effect on her. And she was going into heart failure, but they quickly...so I don't think I would if it involved actually taking anything." (F15E, 75 and over)

"There's a while there when I saw, occasionally you'll see an advertisement, Wanted, Men Wanted in good health between the age of blah blah- but I'm now too, I'm past that- and sometimes I've thought of going there- medical research, but I don't think I'd be wanting to swallow pills- you know if they said, here's a bottle I want you to take this, or here's some pills, I'd just say no." (M2E, 65-74)

## Summary of attitudes towards taking part in research

Participants expressed a range of attitudes to, and reasons for, taking part in research. Overall, people from all groups were willing to take part because of a desire to help others. A strong motivating factor in the English-speaking participants was a sense of obligation to their doctors; a motivating factor amongst the Punjabi participants was a sense of community obligation. Amongst some participants, particularly the ethnic minority participants, there was some misunderstanding about the aim and consequences of taking part in this project.

### **7.5 Chapter summary**

This chapter looked at factors, other than those related directly to questionnaire content, that might influence participants' attitudes, and response, to a health-related survey instrument such as the RAQ. For example, if someone is familiar with filling out questionnaires, they may be more comfortable with the task and give more accurate answers. If an individual is suspicious of authority or has had a negative experience with their own health care, they may choose to withhold information from an interviewer. Alternatively, if they feel they have not received adequate care in the past, they may exaggerate their answers in order to elicit a more concerned response. Their perception of research, their reasons for taking part, and the conditions of questionnaire administration might also influence their motivation to answer accurately.

It was found that attitudes towards questionnaires, research and the health care profession varied between individuals, and such differences may influence RAQ

response. Some themes, such as uncertainty about questionnaires due to their content or the individual's literacy, were more dominant in the ethnic minority participants, particularly the Chinese. In addition, it was found there was some misunderstanding of the nature of this research study; some ethnic minority participants thought it would directly help their own health. English-speaking participants were more likely to have taken part because of their positive relationship with their general practitioner. The effects of participants' experiences of, and attitudes to, questionnaires, the medical profession, and research participation on the way they respond to the RAQ are discussed in Chapter 8.5.

## **Chapter 8**

## **Discussion**

## 8.1 Introduction

This study used qualitative methods to address the feasibility of using an epidemiological instrument- the Rose Angina Questionnaire- in different ethnic and linguistic groups. In doing so, it called into question the assumptions inherent in cross-cultural epidemiological studies and raised a number of important issues for ethnicity-based research. This research also employed a challenging cross-linguistic methodology that will extend the field of cross-cultural work in both qualitative and quantitative fields, and provided further insights into the means required to carry out research using bilingual project workers.

An epidemiological approach assumes that the RAQ's screening questions for angina will provide an accurate assessment of population prevalence of coronary heart disease. When using this questionnaire in different cultural groups, it is assumed that each question is equally appropriate in screening for angina in each culture, and that people from different cultures interpret the questions in the same way. When the questionnaire is used in other languages it is further assumed that different language versions carry the same meaning. Chapter 3 showed that these assumptions may lead to artefactual results. This study set out to investigate these assumptions and hence assess the feasibility of using the RAQ in three different language groups. In addition, there are philosophical and epistemological implications of a study of this nature. This study can illustrate the tension between a positivist paradigm, in which objective measurement of disease states is plausible and philosophically robust, and a social constructivist paradigm, in which disease experience is constructed by the culture and language in which it takes place. This research provided a bridge

between the two paradigms by acknowledging the importance of epidemiological and survey methodology in understanding and ultimately preventing disease, and by seeking to validate survey techniques by investigating their consonance with the culturally and linguistically constructed worlds of questionnaire respondents.

Participants expressed a range of health beliefs and behaviours. Perceptions and significance of pain and chest pain varied. However, whilst there were some themes that varied between groups, no dominant themes in the cultural construction of health, pain or cardiovascular knowledge emerged that might significantly influence RAQ response between language groups. Individual differences such as general anxiety about health, or awareness of cardiac symptoms, could be more likely to affect perception of, and response to, RAQ items. Key translation errors were found in the existing versions of the RAQ that might undermine its cross-cultural comparability. In addition, it was found that standardised administration of questionnaire items by an interviewer might be difficult to establish. This raises doubts about the quality of data on angina prevalence in previous studies with non-English versions.

During the process of carrying out the research, a number of methodological issues emerged that may have affected the results. The process of lay assessment of questionnaire appropriateness using bilingual project workers also raised methodological challenges- the assessment task was difficult for participants to understand and for bilingual project workers to implement. Quality control of data generated by bilingual project workers in languages not spoken by the researcher was



problematic. These issues, in addition to further reflections on the strengths and weaknesses of the study's methods, are discussed in section 8.2. In sections 8.3 and 8.4 respectively, the results obtained in relation to the cultural appropriateness and linguistic equivalence of the RAQ in each language group are discussed. Factors that may affect general questionnaire response tendencies are discussed in section 8.5. In 8.6, future work that may be informed by this study is suggested, and in section 8.7, some final conclusions are drawn and recommendations made.

## **8.2 Discussion of methods**

This section will discuss the study's methods. First, strengths and weaknesses of the study's design are discussed. Second, the challenges encountered whilst carrying out the study, and the lessons learnt from these challenges, are presented.

### **8.2.1 *Inherent strengths and weaknesses***

Despite the methodological challenges encountered, to be discussed in section 8.2.2, this project's design had a number of strengths. The research was participatory and equitable, as recommended in 3.4.3 (e.g. Kai & Hedges 1999). Consulting lay people from both ethnic minority communities and the majority population in Scotland combats ethnocentrism and questions the dominance and relevance of a Western biomedical worldview to non-Western origin populations. The research allowed questionnaire respondents' own voices and opinions to be expressed and considered, an important virtue of qualitative methodology (Jones 2003).

The principles underlying the necessity for careful cross-cultural adaptation of questionnaires have been overlooked in many medical disciplines, particularly cardiovascular epidemiology (Hunt & Bhopal 2003). This project had a cross-disciplinary emphasis, and drew information from areas as diverse as epidemiology, clinical medicine, medical sociology, linguistics, and translation studies. Another strength of this project was that it explored novel territory in the context of cardiovascular epidemiology and built on earlier work (Fischbacher et al. 2001). Integrating different ways of thinking and forms of knowledge may improve the quality of cross-cultural research in this field.

In addition, this project was designed to assess the feasibility of adapting an epidemiological questionnaire for use in multiple ethnic groups, and in the process of doing so to provide insights into the methods required to best carry out meaningful cross-cultural research. Whilst this project yielded specific findings with respect to the cross-cultural adaptation of the Rose Angina Questionnaire, the lessons learnt are generalisable to other questionnaires and self-report instruments. Novel methods (described in 4.12 and discussed further later in this section) were developed to collect and analyse data collected in three different languages; these methods can be refined further and used in future work on the cross-cultural adaptation of questionnaires to increase its validity.

Another strength of this research was that it used versions of the Rose Angina Questionnaire- those developed by the Newcastle Heart Project (Bhopal et al. 1999)- that were translated using the best methods to date. As outlined in chapter 2.7, table

2.5, the methods used by the Newcastle Heart Project team to ensure adequate cross-cultural adaptation of the RAQ were the most sophisticated of a large number of studies using the RAQ in a variety of languages and cultures. The questionnaire was forward and back translated into Punjabi and Cantonese by more than one bilingual translator; subsequently, conferring took place until agreement as to the best translation was reached. Compared to the majority of international studies, which failed to specify any details of the translation process, the Newcastle Heart Project was exemplary. However, it did omit a key stage of cross-cultural adaptation methodology- consultations with monolingual lay people to assess face and content validity of the questionnaire. As mentioned in chapters 2.7 and 3.5, this stage is often overlooked in the cross-cultural adaptation of measurement instruments across all disciplines. This thesis argues that it is a vital component of the cross-cultural adaptation process, without which no questionnaire can be assumed to be valid in the new language version. By investigating whether the Newcastle Heart Project translations of the RAQ are adequate for cross-culturally valid use, this project has demonstrated that an adaptation methodology less laborious than lay assessment is not adequate.

The project was designed to assess the cultural appropriateness and linguistic equivalence of the RAQ in three language groups simultaneously. Research in multiple languages is more time-consuming than research in one non-English language; however, nationally representative multi-ethnic survey research in Britain requires, at minimum, several different language versions of its survey instruments (for example, Hindi, Gujarati, Bengali, Sylheti, Punjabi, Urdu, Cantonese, Mandarin,

and others). Research in three language groups, two of which were non-English, gives insights into the conditions under which multi-ethnic survey researchers would need to assess their questionnaires, and the best methods by which to do so. In addition, as reviewed in chapter 3, confirmation of true cross-cultural validity requires that each language version of a questionnaire is comparable with every other. This project avoids the pitfalls of using the English version as the sole reference version by assessing the acceptability and examining the linguistic equivalence of three languages simultaneously. This helps to avoid the situation in which two different language versions can each be similar in meaning to the English but substantially different in meaning to each other.

The inclusion of an English-speaking group in the qualitative research and lay assessment process adds another strength to this project beyond investigating the feasibility of concomitant research in multiple languages. One of this project's tenets was an anti-ethnocentric approach to multi-ethnic research, and so it was important to avoid a common approach which uses "...'ethnic'...[as] a shorthand for minorities" (Pfeffer 1998, p.1383). Therefore, rather than assuming conceptual appropriateness and lack of ambiguity of meaning in the original English version, this project sought to appraise critically the face and content validity of the RAQ in English speakers in addition to ethnic minority groups. Inclusion of the English-speaking group also provided a link to the body of literature on the validity of the RAQ, largely in white European-origin populations.

Another strength in the study's design was the innovative methods developed for collecting and analysing data in languages not spoken by the researcher, as described in Chapter 4.12. As outlined there, the inclusion of two bilingual project workers in, and the discursive nature of, the process of translating interview data into English for recording by the researcher increased the robustness and verifiability of the findings and allowed for cultural commentary and contextualisation to be considered alongside participants' utterances. The use of two bilingual project workers rather than a single translator acted as a form of triangulation to increase validity of the data. The data were also examined by comparing them with other similar data, in the form of published literature, collected from these groups in a variety of different settings, as illustrated in sections 8.3, 8.4 and 8.5. Further forms of determining the validity of data are possible but were not feasible within the timescale of this study. For example, feeding back findings to respondents, community groups and representatives to check agreement could have verified the results further.

This project had a relatively large sample size for a qualitative research study. It had been intended to interview 20 participants from each of three language groups, and in practice it was possible to interview between 25 and 30 participants from each group. Such a sample cannot make any claims about how the population as a whole understands the concepts underpinning the RAQ, or how it perceives and interprets the items on the questionnaire. However, the study was not designed to make statistical generalisations about a population, but merely to assess the feasibility of adapting the RAQ for use in Punjabi, Cantonese and English speakers. In qualitative research, a small sample is deemed sufficient to address the aims of the study, by in-

depth data generation in the individuals' own words. As stated in Chapter 1, it is important to note that, whilst the possible factors influencing equivalence of the RAQ in English, Punjabi and Cantonese speakers (and particularly the conceptual and functional equivalence) were examined using qualitative techniques, this was not an in-depth medical sociological enquiry but a study designed to investigate a range of factors that might have a bearing on response to an epidemiological questionnaire. As such, the study's methods departed in various ways from traditional in-depth qualitative enquiry. However, as this project's methods were novel, the necessity to depart from more sociological methods emerged throughout the course of the field work. For example, due to the time-consuming nature of coordinating challenging and novel multi-lingual research, and the difference between the type of data generated by the innovative cross-linguistic methods employed on this study and more traditional raw transcript data translated, where necessary, into the researcher's language, it was not possible to carry out rigorous analysis whilst interviews were progressing. Whilst one more traditional approach to qualitative research is to ground emerging theory in the data, modify the methods in order to further test this emergent theory, and continue interviewing until analytic saturation is reached, this approach was not adopted in this project for the practical reasons outlined above. However, due to the sample size, it was possible to have confidence that a wide range of views and opinions were accessed about the conceptual and functional appropriateness of the RAQ in each ethnic group. Similarly, in the RAQ assessment task, a sufficiently large number of Punjabi, Cantonese and English speakers were consulted about the acceptability and interpretation of the RAQ questions to suggest that results may also be meaningful on a larger scale.

This project, however, did have a number of weaknesses in design, some of which were not apparent until during the fieldwork. The main weakness was the lack of direct control over the process and quality of the data gathering due to the researcher's inability to speak two of the three languages under study. This weakness is relevant to all cross-cultural work where the language of research is other than that spoken by the researcher. It is unlikely that any researcher working with multiple ethnic groups will be fluent in all of the relevant languages and cultures and hence be able to gauge directly the equivalence of questionnaires. Therefore, it becomes necessary to work in collaboration with bilingual project workers, who have the necessary linguistic and cultural skills. However, bilingual project workers with no research experience require training in the relevant skills before carrying out fieldwork, and due to lack of academic experience may find the discipline of research challenging. Conversely, experienced researchers who are bilingual in the languages necessary may not be sufficiently similar to the lay community to provide a plausible commentary on the language or cultural issues relevant to monolinguals. Understanding the difficulties of working through project workers who are first, previously untrained and second, carrying out research in other languages is of crucial importance in interpreting and improving both qualitative and quantitative cross-cultural research. Hence the particular methodological challenges encountered whilst working with the bilingual project workers employed on this study, and how they may have affected results, are discussed in depth in the next section.



Another weakness of the research may be the assumption that people from a particular language group share a consistent cultural world-view. As Pfeffer (1998, p. 1382) noted with regard to the constructed categories of 'race', 'ethnicity' and 'culture',

"...the validity of borrowed systems of classification in health and medical research is rarely questioned."

However, whilst there is much heterogeneity between ethnic or cultural groups (and this will be discussed further with reference to this study's findings in sections 8.3 and 8.5), there is still an epidemiological necessity for maximally valid versions of survey instruments for use in other languages and cultures. This project chose to study, in the case of the ethnic minorities, particular language sub-sets of wider ethnic groups, i.e. Pakistani Punjabi speakers and Chinese Cantonese speakers. It may be that, given the interdependent nature of language and culture, that people from the same cultural group who speak the same language may be most likely to have a common world-view. This will be discussed further in section 8.4, when considering the acceptability of the Punjabi version of the RAQ to Pakistani Punjabi speakers- as seen in the results (see 6.2.4 & 6.2.11) the Punjabi used in the questionnaire would be more appropriate for use in an Indian Punjabi group. Similarly, it may be that the conceptual appropriateness of the RAQ and factors influencing questionnaire response tendencies in the Chinese Cantonese-speaking group are different from those found in a Mandarin or Hakka-speaking Chinese group.

Another criticism that might be leveled at this work is whether the data generated via interview about the concepts underpinning RAQ use represent participants' genuine



or 'private' beliefs, as opposed to acceptable 'public' accounts (Cornwell 1984). It has been stated that there is an 'ambiguous relation between language and action' (Lambert & Sevak 1996). As will be discussed further in section 8.3, there may not be concordance between participants' statements about health beliefs and behaviour and their actual beliefs and behaviour. One of the merits of anthropological, indirect techniques such as participant observation is that they do not rely exclusively on participants' narratives but on observation of action also. Lambert & Sevak (1996) argue that a single, one-off interview tends to produce orthodox responses by the participant. The one-off interviews used in this study may be subject to a degree of social orthodoxy in interpersonal communication. However, the methods employed address this criticism. As will be discussed further in section 8.2.2, the Punjabi and Cantonese interviewers were often known to the participant, so an element of initial formality may have been avoided in these cases. There may also be some between-group variation in 'authenticity' of response, either due to differing cultural or linguistic tendencies or the varying modes of sampling and the relationships between the interviewer and the interviewee. For example, the English interviews were carried out by the researcher on a sample of consenting patients who had been randomly selected from GP lists. The interview context was therefore much more formal than many of the ethnic minority interviews, where a relationship between the interviewer and interviewee was already well established. However, the effect of familiarity with the interviewer in these three groups of participants is unknown. It may be that the lack of familiarity with the interviewer in the English-speaking sample meant that participants had less investment in creating a favourable impression to the interviewer and hence responded in a more 'private' manner.

The methods employed in this project were not intended to establish strict equivalence of the RAQ in each language group. This study makes no claims to generalisability and comparison of findings between these three language groups in general since it is not possible to state whether the participants were representative of the wider population from which they were drawn. However, the study was designed to assess the feasibility of establishing equivalence, and as such it was possible to examine the notions of conceptual, lexical and functional equivalence in the participants studied. It is necessary to scrutinize the feasibility of equivalence in this manner, in order to expose areas that may lead to a lack of cross-cultural validity, prior to carrying out validation work and field testing with a representative sample of people from each language group.

### ***8.2.2 Methodological challenges and insights***

Throughout the course of this research, a number of methodological challenges were encountered. Some of these challenges, such as the relative success of different sampling strategies employed and the challenge of gaining ethical approval for the study, have been outlined in chapter 4. This section discusses these challenges further and reflects on the insights gained from them. In addition, the particular issues which emerged whilst working with bilingual project workers are discussed- the use of language tests to select bilingual staff, the training of project workers not experienced in research, their role in recruiting participants for the study, practical and organisational challenges of coordinating and carrying out this type of research, and project workers' effects on data collection. Finally, the effectiveness of the

methods used during the RAQ lay assessment exercise are considered. The lessons learned and insights gained into carrying out research in a range of language groups are important to bear mind for future studies.

#### 8.2.2.1 Sampling

The lower response rates yielded by a GP-based sampling strategy in the ethnic minority groups compared to the English-speaking majority population may be due to a number of reasons, such as lower literacy or more changes of address. However, the most likely reason, according to community groups and project workers representing these communities, is that people from ethnic minority groups do not respond well to postal invitations and are more likely to take part in research if approached by someone recognizably from their own community who gives a verbal explanation of the project and request to take part. The original strategy in this project was to follow postal contact with a telephone call; however, ethical approval for this step without opt-in consent was not given. Other researchers should consider the possibility of a low response rate if sampling in this manner through general practices. However, response rates may vary, depending on the general practice, the staff's relationships with ethnic minority patients, the nature of the request for participation, whether participants from certain groups tend to travel overseas more, or by chance. It is also likely that response rates will be higher if patients are being asked to participate in a study that relates directly to their own medical condition. Supplementing the sampling strategy with a community-based sampling approach was more successful than general practice-based sampling alone and it is recommended that other researchers consider doing likewise. There is, however, a

danger in over-reliance on community groups as the sole sources of participants in ethnicity research. Firstly, the people who attend community groups may not be representative of the community as a whole. Secondly, the individuals who agree or volunteer to take part via this selection strategy may be particular kinds of individuals who are used to speaking out. Thirdly, community groups can become over-researched and disillusioned with the research process through being exhaustively used as a source of research participants. It is important to try a range of sampling techniques in order to sample as wide a variety of people from a certain ethnic group as possible. Snowball sampling may also provide an important link to people who may not otherwise be accessed via community groups or the health care profession (Hughes, Fenton, & Hine 1995; Rankin & Bhopal 2001).

Other researchers have found similar problems with response rates. For example, one study (Conroy & Mayberry 2001) has shown low rates of questionnaire return from South Asians in Leicester, and the authors conclude that:

"...low response rates highlight the difficulty of communication with this group, suggesting that we need to make more resources available to these patients." (p.418)

Other researchers have attempted to access ethnic minority participants via alternative routes. Lambert and Sevak, in their studies of the health beliefs and practices of South Asians living in London, report contacting and interviewing participants in non-health related settings to avoid bias in responses arising from an institutional environment (Lambert & Sevak 1996). They used a random walk method to recruit a Bangladeshi sample, which proved more successful than approaching people within a GP environment. These researchers were also able to

recruit Punjabis successfully using a GP-based strategy- they recruited patients presenting at a surgery. However, their approach relied on face-to-face verbal recruitment rather than written contact. Campbell & MacLean (2002) also report a lengthy process of recruiting from the African-Caribbean community in England, with successful recruitment relying on key contacts through community organisations.

#### 8.2.2.2 Ethical issues

As described in chapter 4, research in Lothians that aims to access participants via GP registers or other NHS lists now requires opt-in consent prior to the patients' contact details being given to the researcher. Whilst this is not yet the case throughout Britain (Raj Bhopal, personal communication), the requirement for patients' consent prior to disclosure of any information by their doctor has been recommended by the General Medical Council (General Medical Council 2000, p.7) and hence may become increasingly widespread. This necessity raises an important ethical debate- the need to obtain patients' informed consent before use of personal information (including ethnicity, name, or telephone number), which may militate against adequate response rates, versus the need to carry out meaningful health-related research in these groups in order to advance knowledge and understanding. It may be that the requirement of written opt-in consent has a more serious impact on the response rates of ethnic minority groups than it does on the response rates of the majority 'white' group. This may be evidenced by the very low response rates in this study by Pakistani and Chinese patients approached in writing by their GP, compared to the higher proportion of English speakers who responded positively to recruitment

via this method (4.8; table 4.2). This may be for a number of reasons. Firstly, literacy and familiarity with official letters may be lower in the ethnic minority groups studied. This may be a function of culture, or a function of socio-economic and educational status. It may be that the English speakers approached by their GP in this study, despite being chosen randomly from the GP lists, had a higher educational/ socio-economic status than the Pakistani or Chinese people contacted. In addition, it may be that the concept of 'informed consent' has different dimensions in different ethnic groups; for example, where cultural groups tend towards a collective emphasis, it is possible that a decision about participation is made not by an individual but by a group or authority figure. For example, it has been reported that, for Chinese-Canadians, the right to make decisions about health care or disclose information is given to family members rather than the individual (Bowman & Hui 2000).

There were also very practical implications of this low response rate. Project workers had been employed and were ready to start work on the study, but due to the small number of opt-in responses by ethnic minority patients, there was very little work for them to do. This led to an unfortunate situation whereby project workers were expecting a certain number of hours of work per week that the researcher was unable to provide for some time. In order to carry out this type of research smoothly, it is important to be aware of the factors, such as recent developments in ethical requirements, that may effect participation in the study. This would make it easier to anticipate delays and to be better informed as to when it is appropriate to recruit employees.

Another issue arising when sampling individuals by ethnicity from NHS registers is the identification of participants. Ethically, practice staff and not researchers should have access to practice registers and scan them to identify participants from a particular ethnic group. In reality, however, practice staff's knowledge of the ethnicity of their patients may be limited. For example, staff members (all white European-origin) in the practices approached in this study were unable to categorically state the ethnicity of their participants, or identify Pakistani (identifiable Muslim names are more likely to be used as a proxy for Pakistani origin) as opposed to Indian (more likely to be Hindu or Sikh). This type of identification of participants from a particular ethnic or national group requires specialist knowledge of regional names; practice staff may not have this specialist knowledge and therefore may be unable to identify potential participants accurately. As mentioned in 4.6, there is computer software available (Nanchahal et al. 2001) to identify South Asian names, but in this study such software did not seem practical or viable to use on a small scale on disparate general practice software and registers. To ensure equity in research, it is important that participants from all ethnic groups are given equal opportunity to participate. The necessity for accurate identification of ethnic minority participants, therefore, may require a debate on the ethical issues surrounding release of personal information, such as name, to researchers without prior consent by the patient.



### 8.2.2.3 Issues arising through work with bilingual co workers

#### *Language tests*

As stated in chapter 4.7, previous literature and personal communications with researchers working in this area had recommended testing bilingual project workers' language skills prior to appointment, as the quality of the data gathered rests to a large extent on these language skills. In practice, it was found that these language tests were difficult to develop and implement, and it was unclear whether they were meaningful. For example, it was difficult to locate an institution that could provide this service. Researchers should be aware that there is a Diploma for Public Service Interpreting (DPSI) granted by the Institute of Linguists ([http://www.iol.org.uk/qualifications/exams\\_dpsi.asp](http://www.iol.org.uk/qualifications/exams_dpsi.asp)), and that these courses take place in various colleges and institutions. In Edinburgh, a local Community-based English as a Second Language organisation ran courses in this diploma program and their staff were able to develop a language test in consultation with the researcher and provide staff to administer the test. However, in some locations, the pool of appropriately qualified staff may be small. For example, in this project, the person approached to administer the Cantonese language test was also one of the applicants for the job. In addition, it proved difficult to find a suitable person to administer the Punjabi test to Pakistani participants. Despite the researcher requesting that the tester was fluent in the Punjabi spoken by the lay Pakistani population, the tester was, in fact, an Indian Punjabi speaker. It may prove similarly difficult in future work to communicate the importance of regional variation in language use to an organisation not familiar with the principles of the research, and which may not appreciate the importance of semantic nuances and variations between different cultural groups



speaking the same language. It has been the researcher's experience that interpreting services often have to 'make do' with someone who is not entirely fluent in a language but who speaks a similar form of the language. For example, in Edinburgh, Bengali speakers are assigned to interpret for Bangladeshi Sylheti speakers. The Bengali speaker can understand the Sylheti speaker and vice versa, but neither is fluent in each other's tongue. It is important to be aware, when conducting research focussing on linguistic issues, that collaborators based in the service provision sector may have a more applied and pragmatic approach to interpretation and translation than the researchers do. This may jeopardise the integrity of linguistic research and indicates that researchers should be extremely clear about the importance of linguistic issues to the outcome of their work.

The language tests were also time-consuming to organise and implement; for example, on the day of the scheduled interviews and tests, the Punjabi-speaking test administrator was unable to attend, necessitating the re-assignment of the task to another Punjabi-speaker, and arranging with shortlisted candidates to return to the department on a second day for language testing. In addition, the reliability of the Diploma in Public Service Interpreting was unclear, as on this occasion one applicant who passed the DPSI did not pass the language test.

### *Training*

Previous literature on how to train bicultural interviewers has placed an emphasis on giving them time to read and discuss relevant academic papers (Small et al. 1999). However the finding from this project's training sessions was that this process, whilst

theoretically desirable, did not yield the expected dividends. The feedback from the project workers indicated that the training sessions were perhaps too academic, particularly the first one. The aim was for the training session to have a genuinely participatory emphasis and to involve the project workers as much as possible in the rationale of the project rather than asking them to function as rote interpreters. However, given the time and budget constraints in this Ph.D. study, it was not possible to offer bilingual project workers sufficient training to lead to a qualification, as offered to community researchers trained in Newcastle for a qualitative study on attitudes to smoking amongst Pakistani and Bangladeshi adults (White et al. 2002). Therefore, much of the information discussed with bilingual project workers concerning qualitative methodology, epidemiology, sampling methodology and cross-cultural measurement seemed superfluous. A quicker training would have explained simply the importance of the study, the aims of the interview process and set forth clearly the questions and areas to be covered in the interview. As will be discussed further later in this section, project workers' understanding of the interview tasks was varied and, in retrospect, it may have generated more consistent and informative data had the training been more prescriptive. In conclusion, a much more practical and less abstract training programme might have been more efficient and yielded equally skilled interviewers.

### *Bilingual project workers and participant recruitment*

Due to the difficulties with the GP-based sampling strategy outlined above, the project workers, after appointment, were asked to assist in recruiting participants. This role had not been part of their original job description, and had not been

considered when budgeting the project. However, the funding granted was sufficient to cover the additional cost. Luckily, most project workers were resourceful and enthusiastic about the project, and played a willing and active role in involving participants from their communities in the project. However, future research will benefit from an awareness that staff may play an important role in participant recruitment, and researchers should budget and train appropriately.

### *Practical and organisational challenges*

This project required flexibility in working hours. Sessional project workers often have other commitments and the time available for group discussion and analysis may be limited to unsociable hours. Throughout this project, evening and weekend analysis sessions with the project workers were the norm. Researchers need to be prepared to work outside normal office hours in order to accommodate sessional staff. In addition to the analysis sessions, the project workers in this study needed to be flexible and committed to out-of-hours work in order to carry out interviews at a time convenient for the participants. It is important that this is clear to project workers at the outset of the project; otherwise, progress may be extremely slow.

Another practical consequence of out-of-hours work was that it was fortunate that all project workers employed on this project had their own transport; were they to have relied on public transport, the late working hours would have been problematic. The job description had not specified that project workers must be able to drive their own vehicle to interviews and analysis sessions late at night; however, it is important to bear this in mind for future work; again, completing interviews may be an extremely

slow process if project workers are not available or able to interview at the times suggested by the participant, often at short notice.

In addition, carrying out this type of work was organisationally challenging. Analysis sessions depended on successful completion of interviews by the project workers, and availability of both project workers from a particular language group at the same time. Whilst it was possible for the researcher to carry out approximately half of the English-speaking interviews prior to commencement of the ethnic minority interviews, and the remaining half once most ethnic minority interviews were completed, running the Pakistani and Chinese interviews simultaneously required a good deal of organisational effort. It was also not uncommon for participants to cancel or reschedule interviews at the last minute, therefore stalling the analysis process and necessitating re-arrangement of meeting times. The demands of keeping the project moving and of providing regular, reliable employment for the project workers meant that there was little time available to reflect on the data being gathered throughout the ethnic minority interview process. Researchers should be aware of the practical and time management difficulties of coordinating research in several different languages and ensure that the resources- such as administrative support- are available to carry out this type of research rigorously. It is also fair to inform bilingual project workers that the work can be unpredictable and inconvenient. Researchers should take into account that turnover of these sessional staff may occur due to the demands of the job in the context of project workers' other commitments. For example, as noted in chapter 4.7, one of the project workers dropped out of the study, necessitating urgent re-recruitment and

training of a replacement. Researchers should keep in contact with a pool of reserve project workers whom they can draw on if necessary. To avoid losing staff, researchers should make efforts to make the conditions of the job appealing. Ideally, enthusiastic project workers should be selected and trained to maximise their sense of commitment to research in their community and investment in its outcome. Whilst it might be more efficient, if resources are limited, to develop an applied training schedule with a minimal academic component, it is nevertheless important that project workers feel that their role is meaningful and has the potential to be collaborative. They should be sufficiently informed of the aims of the research and involved in the evolution of the project to ensure this is the case.

### *Project workers and data collection*

As data collection and translation/preliminary descriptive analysis of interview data proceeded, the fundamental mediatory role played by these project workers was obvious. It was never expected that the project workers would be invisible components of a straightforward translation process; but as the work and interaction developed and unfolded, it became clear that they played a profound role in shaping the data generated. In this section, this finding will be discussed with respect to the qualitative, semi-structured investigation into cultural beliefs, attitudes, experiences and response tendencies. Bilingual project workers' role in the RAQ lay assessment exercise will be considered in the following section as this task was sufficiently challenging from both participants' and interviewers' perspectives to warrant separate discussion.

Firstly, the project workers carried out the interviews entirely alone; they were not acting as third-party interpreters for an English-speaking researcher's questions. Presentation of the project to the participant was therefore done, in the field, by the project worker. Despite the researcher's attempts to standardise this and ensure similarity to the way the English-speaking interviews were carried out, it emerged gradually through feedback and commentary sessions that distinct interviewing techniques, styles and focuses were being employed. Each project worker's understanding of the project varied, reflected in the way they presented the research and RAQ assessment task to their interviewees, and this in turn varied from the initial interview template used by the researcher whilst carrying out the English-speaking interviews. Project workers became entrenched in using their own terminology, style of questioning and sequence of questions and it was found that it was difficult to intervene and change that style once it was established. All the project workers repeatedly focussed on the questions they found most meaningful or were most comfortable with, despite the researcher's reiteration throughout the project of the key core questions and focus. For example, one project worker would always ask people to define what they meant by health, whilst another would be particularly tenacious in coaxing people to describe their eating habits and regularity of meals.

Anonymity, or the absence of it, emerged as a major issue throughout the fieldwork. Edinburgh in particular (and Scotland in general) has, unlike areas of England, relatively small ethnic minority communities. People in these communities will know many other members of their community, either directly or indirectly. Due to

the central role the project workers played in recruitment, many participants also had a previous personal or professional relationship with the project worker (for example, the multiple professional roles of one of the female Cantonese project workers are discussed below). Perhaps the pool of individuals qualified to carry out work of this nature is likely to be small and the same faces recur in all similar health or social research, or when an interpreter or translator is required. As outlined in chapter 4.7, each project worker signed an oath of confidentiality and during training the concepts of anonymity and non-disclosure of data, including personal information, were discussed in depth. However, despite the researchers' insistence that participants should be identified only by their participant identification number and not by name, some project workers' tendency was still to discuss personal information about the participant during taped analysis sessions. The researcher had to be vigilant in reminding them that social comment about a research participant was inappropriate.

In addition, the likelihood is that the project worker, as interviewer, is a very important part of the interview process from the perspective of the interviewee. The project worker is someone who speaks the interviewee's language; who is part of the same community; who is probably known by family, status or reputation, and who will be judged in that manner. There was some divergence here amongst the Chinese and the Pakistani participants. The Chinese participants, on the whole, appeared less mistrustful or wary of revealing personal information to the project workers than the Pakistani participants did. Two Pakistani participants specifically stated that they did not want the Punjabi-speaking project worker who was not interviewing them, who



was known to them socially, to listen to their interviews, and only agreed to be interviewed provided this was not the case. This produced a delicate situation in which it was necessary that the project worker in question was not informed of these participants' wishes, or indeed of their participation, in order not to give offence.

This personal relationship between interviewer and interviewee was absent from the English-speaking interviewees who were recruited through a general practice. Participants recruited in this way were unknown to the researcher. The possible effects of familiarity on interview data have been discussed above in 8.2.1.

One Cantonese speaking project worker was a full-time council-employed interpreter, and therefore of some professional standing and well known to the participants. The majority of her interpreting work took place in a medical context. Because of this role, it was common for her interviewees to find it odd that she was asking them questions to which she already knew the answers. As instructed by the researcher, during the interview she repeatedly reassured participants that she was not there in her usual capacity and that she could not assume any knowledge about their health, in order to make sure that people voiced information that otherwise would have not been made explicit. However, during the translation and analysis sessions, this project worker tended to report interview data using medical terminology. The researcher was surprised that Chinese lay people would use these terms, and therefore discussed these translations with the project worker. It became clear that she was paraphrasing a lay Chinese term into a medical Western term. For example, she informed the researcher that an elderly community member will say



'*soon fung*', literally 'damp wind' but this will be translated as 'rheumatic pain'. For a non-Cantonese speaking researcher, this translation into the English may give an impression of biomedical sophistication in the discourse of the interviewees that is not present. Researchers should be careful to impress upon bilingual staff the importance of translating concepts into English in a manner that is not misleading in this way. Despite not having carried out research interviews before, the Chinese project worker in question was extremely reflexive and insightful; however, her day-to-day interaction with medical staff may have caused her to express herself in medical terms. The tendency for some interpreters in a medical or clinical environment to avoid potential 'loss of face' by filtering out traditional, non-biomedical terms has been reviewed (Cambridge 1999). In this case, it may have been difficult for the Chinese project worker to disentangle her roles as project worker and council medical interpreter. This example illustrates that project workers' other roles can effect the way they carry out research. In all the workers, the tendency to interpret (in the analytical sense) in addition to interpreting from one language to another appeared to be strong. Interpreters might provide a meta-commentary upon, or extrapolation of, what the lay person has said. This is not always apparent to the researcher who may assume the words are the participants' own. Another project worker prefaced many statements with "Basically what she is trying to say is...". It was very difficult to convey to them that it was necessary to hear what the interviewee is saying in their own words, without undervaluing the project worker's contribution. It may be that, whilst the principles of translation and the importance of retention of meaning of text or speech are well-known, both in the academic literature and by the teachers and trainers on interpreting courses such as

the Diploma for Public Service Interpreting, these principles are not always implemented in practice by community interpreters. As mentioned above, Cambridge (1999) has commented on the well-established knowledge that 'linguistic mediators' (less professional interpreters) can tend to interpret in a certain way to avoid being seen as responsible for a statement that might cause loss of face to themselves or their community. It is possible that the bilingual project workers felt it was necessary to present a particular image to the English-speaking academic researcher, and that this distorted their interpretation of participants' speech. Temple (1997) has noted the importance of the relative status of translator or interpreter and researcher in influencing the quality of translation of research data and emphasised the central role research translators play in shaping the researcher's perspective on the data. Twinn (1997) has compared the categories and themes generated from qualitative interviews when translated into English and analysed in their original Chinese. She found no significant differences in major categories generated, but some variation in minor themes. However, in Twinn's (1997) study, the interviews were translated and analysed by bilingual research assistants rather than community interpreters untrained in research, and it is possible that the lack of differences between the analysis of the English and Chinese interviews was due to the similarity in research training between data analysers.

The interviews in this case study were deliberately semi-structured and the topic guide used open-ended questions as much as possible. This was in keeping with the spirit of qualitative research, in which participants' own lived experience is allowed to emerge in the participants' own words and with their priorities. However in

retrospect, given the disparate data collected, it may have been advisable to be more prescriptive in the question schedule to ensure more uniformity between individuals and groups. This approach requires testing to confirm whether it is preferable to a less structured interview guide.

#### 8.2.2.4 Lay assessment of the RAQ

Participants from all ethnic groups found it very difficult to appreciate that they were being asked to comment on the understandability and acceptability of the questions in their language and often spontaneously answered the question instead. This may have been because the questions were not obviously nonsensical or non-grammatical. However, it is important not to assume that ready answering of a question equates with full understanding of the question. As shown in the results (6.2.1) subsequent probing revealed that participants were often answering questions other than those intended due to translation and interpretation errors- for example, when answering 'Yes' to the question "Have you ever had any pain or discomfort in your chest?" some Pakistani and Chinese women were referring to pain in their breasts. Many participants were unable to stop answering the questions directly even when reminded repeatedly that they were not being asked to do so. Project workers often gave up reminding them or the exercise was reduced to a simple 'Did you understand that?' type of rote questioning. Some participants were able to grasp the abstract nature of the task. However, others struggled to understand what they were being asked to do and some became obviously tired, annoyed and confused by the questioning, such as the Chinese participant who snapped, "I don't understand your stuff, Miss!" to the project worker (6.2.6). This was not only the case in the ethnic

minority interviews; the researcher found that asking some English-speakers to comment on their understanding of common phrases was also met with bewilderment. It is important for researchers to be aware that this kind of abstract task, where lay people are asked to comment on their understanding of common terms and questions, can be problematic. It may be that lay people from different ethnic groups are unused to giving their opinion on matters such as these, and consider them the domain of professionals. Alternatively, if the relevant version of the RAQ uses straightforward language and common phrases, the task may seem so simplistic as to be irrelevant and confusing. Despite the recommendations in the literature to involve monolingual lay people in the assessment of cultural and linguistic acceptability of a survey instruments (see 3.4.2), this study found that the task was difficult to implement. Previous research carrying out 'think aloud' interviews with low-income African American, Chinese, Latina and Vietnamese women in California found similar results (Pasick et al. 2001). 'Think aloud' interviews required the women to report on their cognitive processes and understandings whilst answering a survey question in their language, whether they could rephrase the question in a better way and whether they thought people would give truthful answers. Pasick et al found that these think-aloud interviews were too challenging for minimally educated respondents, who were not accustomed to being asked such questions and found the task embarrassing.

Researchers should, therefore, bear in mind the practical challenges involved in involving lay people in direct assessment of questions. Careful explanation of the task in simple language may facilitate the process. It may also be important to

emphasize to participants that their opinions are both valid and valuable, as participants may be reluctant to correct questionnaire translations. For example, this study found that one participant, after suggesting a better way to phrase a question, told the project worker not to correct it on their questionnaire 'because maybe it was OK' (6.2.4). Whilst one Cantonese speaker was able to comment that a translation seemed to have been made literally from the English and hence not in the best Cantonese (6.2.11) the project workers felt he was an educated minority. It may be that some lay people do not perceive themselves as qualified to correct questions developed by survey professionals, and are anxious when doing so. It is possible that some participants in this study agreed that a translation was acceptable because of this reluctance to be critical. This could be overcome in future by project workers explaining that translations are often inappropriate, and that it is important to find out how ordinary people from their community speak and understand questions about the topic under study. However, where participants did not suggest a better way of phrasing the question, this could also be due to either a genuine acceptance of the question, an inability to think of a preferable alternative, or a lack of sufficient probing by the project worker or researcher (discussed further below). Another finding from this study was that certain ways of asking a question could elicit a response, whilst others did not. For example, when asked why she thought an interviewer would be asking her a question about severe pain in her chest, a Pakistani woman was unable to answer the question. Had the project worker stopped questioning at that stage, it would have been assumed that the participant was not aware that the question was querying symptoms of a heart attack. However, when the project worker asked the participant why a doctor would ask her a similar

question, the participant was able to illustrate awareness of the symptoms of MI by responding that the doctor would be asking about a heart attack (6.2.11).

The administration of the lay assessment task by the bilingual project workers was also problematic. Despite the training given, project workers carried out the RAQ assessment exercise in different ways. As outlined in chapter 4, project workers were instructed to read out each question on the RAQ and ask the participant what their opinion of the question was, if they could think of a better way of asking the question, and to probe the participant's understanding of each word and phrase in more depth. However, these instructions did not seem to be adhered to. It is important to be aware that it is difficult for an English-speaking researcher to directly monitor the exchange during the interview when listening to the re-playing of interview tapes and relying on a verbal translation by the project workers. Ideally, the team overseeing research such as this should contain researchers bilingual in the requisite languages. The tendency of some project workers may be to summarise or paraphrase what was happening in the interview, and a solely English-speaking researcher will be unaware of the specifics of the exchange. However, in this study, it was sometimes difficult to know when this was happening. Researchers should be vigilant in encouraging project workers to give exact translations and to avoid condensing information. Overall, none of the project workers were comfortable with administering the RAQ assessment task. All expressed frustration and trepidation about this part of the interview. Whilst the initial instruction had been to carry out this task at the end of the interview, one project worker chose to "get it over with at the start so I can relax". Once the researcher was aware the project worker was doing



this, it was allowed to continue. It was considered important to be responsive to project workers' own opinions concerning the interview, based on their experience in the field and within their own community, and to modify the schedule accordingly in order to find the best way of carrying out the research. By the time this particular project worker moved the RAQ exercise from the end to the beginning of the interview process, previous experience had demonstrated that not only did participants often respond minimally to this exercise, the project workers themselves had real difficulty grasping the goal and aim of the exercise. For example, one project worker did not carry out the RAQ assessment task correctly until the third interview despite repeated individual explanation, group discussion and role-playing. Having failed to understand the task, the project worker in question instead had asked the first two interviewees to answer the RAQ questions rather than assess their acceptability.

In addition, it was not until quite late in the project that the researcher became aware, via a third, replacement Punjabi-speaking project worker, that one of the Pakistani project workers was not asking the Punjabi RAQ questions precisely as they had been developed by the Newcastle Heart Project. The project worker's tendency was to elaborate or paraphrase the questions, or to introduce some English or Urdu words, again despite extensive and repeated explanation of the RAQ task by the researcher and the other Punjabi-speaking project worker. For example, the RAQ translation for 'severe pain' in Punjabi is *sakht dard*. However, one project worker replaced this with *shadeed dard*, *shadeed* being an Urdu word for 'severe'. It is unclear why the project worker did this- they may have fundamentally misunderstood the nature of

the task. Due to the language barrier, it was impossible for the English-speaking researcher to monitor this, which has implications for quality control of multilingual research teams. Measures need to be put in place to ensure questions are being asked in the manner agreed upon, and a third translator is therefore vital to point out any discrepancies.

It is also vital to ensure strict training of survey questionnaire interviewers given this study's finding that the tendency in both ethnic minority groups was for project workers to give elaborative translations of the RAQ questions in response to a participant's query about the question, despite being reminded of the necessity for standard administration of an RAQ item. This introduced variation into the questionnaire exercise in this study, and on a wider survey basis may magnify the lack of cross-cultural comparability of data. Also, the rigour with which specific words and phrases were probed varied between project workers (and the researcher) and between interviews; for example, the meaning of 'ordinary pace' was probed in only a small number of Punjabi interviews and the meaning of 'severe pain' probed in only two of the Cantonese interviews. This variation in probing the meaning of certain words and phrases reduced the study's effectiveness in investigating the linguistic equivalence of some RAQ items across the groups studied. This is discussed further in 8.4.3.

The English-speaking researcher was able to empathise with the project workers' discomfort with the RAQ assessment task, having carried out the task in the English interviews. It was found that repeated attempts to engage with a task that clearly



confused participants, and which they continued to be unable to respond to appropriately, led to a feeling of discomfort and awkwardness on the researcher's behalf. Consequently, the urge to finish the task quickly in a cursory manner was strong.

As with general qualitative interviewing, the best way of ensuring adequacy of data in a lay questionnaire assessment task may be to be extremely prescriptive to project workers. It may be beneficial to not only list the exact questions and probes they must ask about each item, but to emphasise the importance of strict and rigorous adherence to the interview schedule even if the task is repetitive or uncomfortable.

### **8.3 Cultural appropriateness of concepts underpinning the RAQ**

The intention of this part of the study was to ensure equivalence between the health-related world-view of RAQ respondents and the concepts underpinning the RAQ itself. In chapter 1, it was reported that minority groups can be viewed as muted within a dominant society (Coffey, Holbrook, & Atkinson 1996), and that assuming health-related questionnaires developed in the language of Western biomedicine are appropriate for other cultures or sub-cultures could be viewed as reducing certain groups to subjugated objects of a dominant biomedical discourse. This research allowed participants' own definitions and constructs of health (their 'explanatory models' according to Kleinman (1980), as reviewed in 3.6) to emerge in order to investigate whether they were dissonant with the dominant biomedical discourse.

It was found that, overall, the concepts underlying the RAQ were similarly appropriate to all three groups studied. A wide range of individual differences were found in attitudes to health, illness and pain and in knowledge of general and cardiac medical symptoms, and these may be more likely to affect RAQ responses than broad cultural beliefs. This finding could be due to the processes of acculturation in different ethnic groups in Britain, where biomedical knowledge is widely accessible to people from all cultural groups. Whilst the language barrier was an issue for the ethnic minority groups, and in particular the Chinese, there were culture-specific health initiatives through both the media and community health promotion that reinforced Western biomedical health beliefs. Similarly, people from other ethnic groups who had lived in Britain for any length of time were likely to be familiar with the health care system here; this may have led to an internalisation of biomedical beliefs. Whilst these beliefs did co-exist with some traditional health beliefs in the ethnic minority groups, the traditional views were unlikely to have any affect on RAQ response. It is important to be aware that cultures are not 'fixed products but dynamic processes' (Pfeffer 1998), and that it is to be expected that ethnic groups in Britain are becoming less distinct categories with separate systems of belief. It is also important to bear in mind that there much heterogeneity within a defined ethnic, cultural or linguistic group and it is increasingly likely that individuals within a certain group display a wide range of beliefs, attitudes and behaviours (Graham-Garcia et al. 2001). This study found that heterogeneity of experience and attitudes were common both within and across groups, and that there was significant homogeneity across groups in terms of beliefs about health and illness. Therefore, within this interview sample, in general there appeared to be no significant cultural

dissonance that would render the RAQ inappropriate for use in these groups. However, there were a small number of issues emerging in different groups, such a minority of Chinese participants relating angina to their stomach, that could undermine comparability of the RAQ across groups if present on a larger scale. Findings such as these would need to be investigated in more depth to ensure strict cross-cultural comparability of a survey questionnaire.

Further investigation into whether this is an interpretation more widespread would be appropriate.

The following results will be discussed in detail: general health beliefs and behaviour (8.3.1); knowledge of angina and heart disease (8.3.2); and attitudes to pain (8.3.3).

### **8.3.1        *General health beliefs and behaviour***

Overall, participants from all groups expressed a broadly similar range of health and illness experience, beliefs about illness causality, and concerns about health. As outlined in 5.2.5, it is more likely that in the groups studied individual differences rather than varying cultural constructions of health would influence the way a respondent perceives the RAQ. However, there were some cultural tendencies in this sample that may have an effect on the cross-cultural comparability of the RAQ if representative of the wider group. For example, English-speaking participants were particularly likely to speak positively about their health (5.2.1). It is possible that this approach to conceptualising and expressing illness may represent a genuine difference between cultural groups. If so, this would mean that an English-speaking

sample would be less likely to report symptoms of illness, and therefore to admit to the symptoms of chest pain queried in the RAQ, than a Pakistani Punjabi-speaking group or a Chinese Cantonese-speaking group. This may lead to an under-estimate of the actual prevalence of angina in a European English-speaking sample.

However, there may be alternative explanations for this finding. The study took place in Edinburgh, and the majority of the English speakers were Scottish. It may be that the positivity displayed was a Scottish phenomenon rather than a British trait; historically and anecdotally there are regional variations in beliefs and behaviour throughout Britain, although it is likely that regional 'character' is much less defined in today's society, where there is so much shared information within Western culture and people are increasingly mobile geographically. Alternatively, this finding of a more positive reporting of their health in the English-speaking interviewees may be due to chance or to interviewer effect. Another explanation is the difference in sampling procedure between language groups. As shown in chapter 4.10, Table 4.3 and discussed in 8.2.2.1 above, the English-speaking participants had volunteered to take part in the study in response to a letter sent to them by their General Practice. In contrast, the majority of ethnic minority participants had agreed to take part in response to a request to do so by project worker from their own community. These different sampling strategies might have selected different types of individuals; it is possible that the English participants who chose to take part in a research study in response to a letter from their doctor were more proactive individuals with a tendency towards optimism and a positive outlook on life. Survey respondents who speak positively about their health may be more likely to answer 'no' to the items on the Rose Angina Questionnaire querying presence of angina symptoms.

Overall, participants from all groups tended to conceptualise influences on health in similar and multifactorial ways; behavioural factors, aging, psychosocial factors, environmental and inherited influences were all seen as part of health. There was no reason to believe from the data generated in this study that there were significant cultural beliefs about health and its causes that would influence differently the response to the Rose Angina Questionnaire in these samples. Some culture-specific beliefs emerged, such as the Chinese concept of *chi* or life force, and the ethnic minority conceptualisation of foods into those with 'hot' and 'cold' properties with different effects on health. Some of these findings have been reported previously, such as the concept of *bhye bhaddi* expressed by Punjabi-speakers in this study has been noted previously (Bhopal 1986b). However, it is unlikely that these beliefs would affect responses to the RAQ. Research with 'Asians' in Glasgow has found that health beliefs, including those about cardiovascular risk factors, were based largely on the Western model of health (Bhopal 1986a); similarly, Koo (1987) has reported that Chinese people in Hong Kong are familiar with the Western model of disease prevention.

In addition, participants from all ethnic groups, including the Pakistani group, noted that exercise had a beneficial effect on health. Punjabi speakers spoke about the beneficial effects of exercise, and showed awareness that a range of daily activities constituted recommended moderate exercise. Some researchers have found that the South Asian population is less likely to take part in physical activity than the general population in Britain, and argue that reduced levels of exercise may be one of the

reasons why South Asians have a higher rate of coronary heart disease, exercise being postulated as cardioprotective (Lip et al. 1996).

As in all groups, merely because a person has remembered and can reproduce a health promotion message does not mean that they implement this message in their lives. It may be that the Pakistani participants in this study who spoke about the beneficial effects of exercise did not actually take any more exercise than those who did not mention it as protective to their health. It is possible that genuine cultural differences exist in levels of physical activity, which may affect RAQ response by decreasing or increasing the likelihood that a person from a particular ethnic group exerts themselves sufficiently to experience angina symptoms. This issue of varying levels of normative physical activity between groups requires further research. However, current methods of measuring physical activity may be culturally prejudiced and may not be robust.

It was demonstrated in chapter 3.7.4 that people are more likely to report pain (particularly cardiac pain) if they are anxious, either generally or about their health. It could also be argued that if a particular condition or illness is more of a concern in one culture, individuals from that culture might be more likely to respond in a way that yields a positive diagnosis. However, the results showed that no group expressed strong concern about angina or heart disease that would be likely to influence their RAQ response (see 5.2.3).

Previous work has suggested that women are more concerned about cancer than about cardiovascular diseases (Wilcox et al. 2002). Overall, this did not seem to be the case with the women in this study. Whilst some Chinese women interpreted the RAQ question about pain or discomfort in their chest to be referring to breast cancer, this may be due to the translation of the question (see also section 8.4.1 below). An American study has found that Chinese women in the U.S.A felt expressed a sense of invulnerability to breast cancer (Facione, Giancarlo, & Chan 2000). However, in this study, cancer in general was perceived as a health concern by both Chinese men and women. Project workers also perceived cancer to be a salient concern in the Chinese community, particularly among the elderly. This concern might have potential implications for RAQ response, if it lead to a tendency to over-report non-cardiac chest pain symptoms if respondents thought such symptoms indicated cancer.

It was postulated that an individual's knowledge of the Western biomedical model might influence their familiarity with the language and constructs used in the RAQ, and therefore might influence the ease of response. In order to investigate this, participants were asked from where they got their information about health. Participants from all groups reported multiple sources of health-related information, including friends and family and the media. However, amongst some participants, GPs tended not to be seen as a source of health information (see 5.2.4). This may be because people are reluctant to bother their doctor with general health queries, or because of the lack of time available in a general practitioner consultation. Another explanation is that people prefer to rely on the other less formal sources of information about health mentioned above. However, amongst the participants from



the ethnic minority groups who were less fluent in English, particularly the Chinese, it is possible that the language barrier was a factor in the tendency not to gain health-related information from their doctor. It has been noted that "multiculturalism presents linguistic obstacles to health care provision" (Lau, Stewart, & Fielding 2001, p.217), a statement supported by this case study, as language was an issue raised by the non-English speakers. Inability to communicate effectively with their doctor or health care provider, and to understand information received from them, may affect different ethnic groups' knowledge and awareness of medical symptoms and signs, which in turn may affect their response to standard questionnaires probing these symptoms or conditions. Many other studies have corroborated the language barrier as a major difficulty amongst various ethnic minority groups in accessing and using health services in Britain (Hawthorne 1994). In an interview study with Pakistani women in the UK, Wilkinson (2001) found that language limitations prevented health problem disclosure to medical staff and inhibited full understanding of health care advice given; Farooqi (2000) has also found that South Asian women reported that language was a barrier to accessing health services, and Liao & McIlwaine (1995) have reported a similar finding amongst the Chinese population in Glasgow. The involvement of family members as interpreters, as reported by some ethnic minority participants in this case study, is problematic. Studies have shown that serious miscommunications can arise in a clinical encounter through the use of untrained interpreters (Cambridge 1999; Ebden et al. 1998; Laws et al. 2004).

The current project found that some Pakistani participants showed awareness that health information leaflets were available in their language through their GP or other



sources. One source of health information targeted towards the ethnic minority groups were health talks at community groups and health promotion initiatives. Pakistani participants commonly mentioned these, which may indicate a successful attempt at health education within the Pakistani (and wider South Asian) community in Edinburgh. Despite similar talks being common in the Chinese community, they were rarely mentioned by Cantonese-speaking participants. The project workers' view (as interpreters and community members, the project workers were often present at such talks) was that some participants had certainly been present at arranged health talks but clearly they didn't remember, didn't understand the question or the talk had made no impact on them.

In addition to community-group organised health education, however, participants from all groups seemed to have access to a variety of information, particularly from TV, magazines and newspapers in their language. Based on the evidence from this study, there were few cultural differences in potential exposure to Western health promotion. However, other authors have commented on the disparities in health education materials across ethnic groups in Britain (Bhopal 1991) and more specifically in Lothian, where the current study took place (Morrissey 2003).

### **8.3.2      *Awareness of chest pain, angina and CHD***

In all language groups, there was variation in the interpretation and expression of the experience of chest pain, and familiarity with biomedical explanations of angina and heart disease. However, this knowledge did not differ substantially between the groups studied and may indicate that, in a wider population, awareness of heart

problems covers a similar range, from the ill-informed to the knowledgeable. It has been reported that South Asians were fairly well-informed about factors relating to cardiovascular health (Beishon & Nazroo 1997). Conversely, Rankin and Bhopal (2001) found that South Asians, particularly Bangladeshis, showed sub-optimal awareness of heart disease, coronary risk factors and prevention. However, the findings from this case study indicate that, in Edinburgh, the Pakistani participants were able to produce a similar range of risk factors for angina and heart disease as the English and Chinese participants. Whilst some participants from all groups had little knowledge of the symptoms, mechanisms and causes of angina and heart disease, others were able to cite classical symptoms and treatment, and were able to identify, for example, diet, lack of exercise, stress, or hereditary factors as possible causes. Many participants with good knowledge about heart disease and angina had personal or familial experience of these conditions. This finding of variation within a certain group in relation to cardiovascular beliefs and knowledge has been replicated elsewhere; Farooqi (2000) has reported that South Asian women expressed a range of opinions and knowledge regarding CHD risk factors.

The majority of participants, whether or not they had experienced angina, did express the view that chest pain was related to a problem with the heart. However, a minority interpreted chest pain as being respiratory, gastrointestinal or injury-related. For example, as shown in 5.3.1, a minority of Chinese participants thought that angina might be related to the stomach. This issue is addressed additionally in section 8.4.2 in which participants' assessments of the intention of RAQ questions about chest pain are discussed. This finding could indicate that the RAQ might be

interpreted by some Chinese participants as relating to stomach pain, leading to inaccurate epidemiological assessments of angina. As mentioned earlier, this would need to be investigated further as to whether this was a view more widely held in the Chinese population. However, there were no other obvious between-group differences in the way Punjabi, Cantonese and English speakers perceived, interpreted and expressed chest pain, awareness of angina or knowledge about heart disease.

For participants reporting a diagnosis of angina or heart disease, there was no clear difference between groups in reporting their symptoms. However, as the Rose Angina Questionnaire is focussed on exertional chest pain in diagnosing angina, it may be inadequate for application in cultures or sub-groups that perceive and express their main angina or cardiac symptom as breathlessness; for example, it has been demonstrated that black patients in the USA were twice as likely as white patients to complain of breathlessness when presenting with acute myocardial infarction (Perkoff & Strand 1973).

However, some individuals expressed views about angina and heart disease that may lead to mistaken responses to a survey question about whether a doctor has diagnosed angina, often used to supplement or validate RAQ angina. For example, one Cantonese man thought that angina (*sum gau tung*, literally 'heart twisting pain') meant unhappiness or irritation; this man would therefore interpret a question about a doctor's diagnosis of angina as referring to whether a doctor had diagnosed him with unhappiness. If this interpretation was held by a wider section of the population

from which these samples were drawn, this might lead to a genuine cross-cultural bias in answering this question.

In contrast to the findings of studies documenting a relationship between the expression of heart pain and psychological distress in South Asians (as reviewed in 3.7.4)- Krause's (1989) work on 'sinking heart' in Punjabis and Fenton & Sadiq-Sangster's (1996) research on South Asian women's 'thinking too much in the heart'- this study found no such phenomenon. The Pakistani men and women often used the term *soch* meaning 'thinking too much, thinking seriously' but did not relate this linguistically to the heart or *dil*. However, 'heart discomfort' or *sum ng su fo* was used as a metaphor for psychological distress in the Cantonese-speaking group. In addition, participants from all groups did view psychological distress as a cause of heart disease (see 5.3.7).

### **8.3.3 Pain**

Beliefs and definitions about pain and discomfort may affect the way individuals or cultural groups respond to questions using these words. In the context of the RAQ, the English words 'pain' and 'discomfort' assume that these are sensations with a physical aetiology. In the language of Western biomedicine, pain has been defined as:

"...an uncomfortable, unpleasant sensation, related to current or impending tissue damage, that motivates the sufferer to avoid the perceived pain stimulus." (Bates & Edwards 1992, pp.63-64)

However, lay interpretations of the word 'pain' (and the associated concept in the RAQ, 'discomfort') may differ from the definition above; for example, pain may also

relate to spiritual or moral suffering rather than tissue damage. Fabrega and Tyma (1976) have illustrated how the meaning attached to the word 'pain' can vary over time; the English 'pain' derives from the Latin '*poena*', meaning 'punishment, penalty, fine, tax' and in Old English the term '*peyne*' related to punishment for crime or wrongdoing. However, English-speaking participants in this case study did not express a connotation of punishment when describing their experience and understanding of pain. Once the English words are translated into Cantonese and Punjabi, it cannot be assumed that these words have equivalent meanings. This topic is discussed further in 8.4.2, which outlines the lay assessment of RAQ translations.

In 3.7.1, it was shown that many studies have reported variation in pain expression and significance between different ethnic groups. However, this study found that all groups showed a variety of individual differences in participants' attitudes to pain and that there was similarity between cultural groups in the way people spoke about pain overall. A range of pain experiences was described that related to physical injury or illness, indicating at least partial similarity in conceptualisation of pain in each culture. However, some alternative definitions of pain emerged. For example, as shown in 5.4.1, one Chinese participant divided pain into two types: bone pain and flesh pain. Another theme in the Chinese group was that *tung*, a translation for 'pain', could refer to either physical sensations or psychological experiences such as depression and worry. Similarly, as shown in 6.2.1 and discussed further in 8.4.2 below, the Punjabi and Cantonese translations for 'discomfort', *takleef* and *ng su fo*, also included a psychosocial dimension.

This division of pain into two different types of experience- physical suffering and psychological suffering- is distinct from the two components in a single experience of pain that have been reported: pain as a sensation and pain as a subsequent psychic experience (Linn, Ware, & Greenfield 1980). This definition acknowledges that whilst a noxious stimulus may be similar, the psychic experience of pain is a separate consequence and may be affected by other factors.

Themes of stoicism and self-management of pain emerged from the enquiry. However, the Cantonese project workers were of the opinion that Chinese people tended to like to take medication more than other cultures, and perhaps were more prepared to respond to pain with medication rather than with the stoic attitude and self-management sometimes expressed by other participants. In contrast, it has been reported that white people were more likely to use pain-relieving medication in a clinical context than other ethnic groups (Streltzer & Wade 1981). It is possible that variations in project worker probing may have influenced the results; for example, as shown in chapter 5.4.2, Punjabi-speaking project workers did not ask participants to rate their tolerance to pain.

Many people had difficulty in expressing the nature of their pain, often using physical gestures (including the project workers when trying to translate a pain descriptor to the researcher) to communicate the experience. In Rose's original publication of the RAQ (Rose 1962), there was an optional section in which there was a checklist of pain descriptors in English (heaviness, burning, tightness, stabbing, pressure), based on answers given by 36 patients with angina when asked

to describe the sensation. One wonders to what extent these are representative of the type of words that people from various ethnic groups would use to describe angina. In English, there are certain words commonly associated with pain, such as nagging or stabbing, and cardiac pain is promoted as being a particular type of pain- often 'tight' or 'crushing'. However, these words may be enshrined in the medical literature and influenced further lay descriptions of cardiac pain. It is possible that some lay people may not otherwise spontaneously use these terms. This has implications for a doctor's diagnosis of angina in English-speaking groups, and more so for immigrant groups to the UK, in which a diagnosis relies on a translation that uses the pain descriptors recognisable to an English-speaking doctor as being representative of cardiac pain. As reviewed in 3.7.2, it has been found Bangladeshi patients tend to give non-classical descriptions of the pain of myocardial infarction, which may delay diagnosis and treatment (Barakat et al. 2003); this might be found in other ethnic groups and also with respect to angina pain. However, the current versions of the Rose Angina Questionnaire use no secondary pain descriptors, and simply ask about pain or discomfort.

It has been stated that:

"According to Fabrega and Tyma (1976), in order to fully understand a description of pain one should examine the sources of the metaphor with which the pain is being described, for it involves a local semantic framework which is rooted in historical and cultural forces." (Yazar & Littlewood 2001, p.25)

It is outwith the scope of this thesis to deconstruct the metaphors used in different languages and trace their historical evolution. However it is important to note that pain descriptors are not necessarily easily translatable across cultures; they are



complex historical concepts that may not transfer simply into another language. In this study, the interview data from the English and Pakistani group suggested that descriptors involving intensity of pain were more common than descriptors about the nature of the pain. However, the Chinese participants did use a wide range of descriptors about the nature of the pain in addition to mentioning its intensity. This may be due to a genuine variation in the vocabulary of pain between languages, or it is possible that the difference between groups is due to variation in interviewers' probing. Another study investigating Chinese pain descriptors reported that Chinese people more commonly described the nature of the pain (in 41% of cases) than the intensity of the pain (20%) (Chung et al. 2001). Often the Cantonese words were not easily translated into English by the project workers, and, as mentioned above, they needed to use physical gestures to communicate the nature of the experience. This has implications for Chinese-speakers attempting to communicate their pain sensation to an English-speaking doctor via an interpreter. It might be difficult to correctly communicate the nature of the patient's experience, and a doctor trained in classical biomedical symptoms of angina and heart disease may not give a diagnosis of angina to a patient who does not use these terms.

One explanation for any uniformity found in this study between groups may be that suggested by Greenwald (1991): assimilation of ethnic groups into a host culture may result in the differences in pain perception and health-related beliefs and behaviours disappearing. Indeed, the finding from this study that the Pakistani participants used English words to describe pain, for example 'tight' or 'nagging' pain (5.4.1), may indicate that the acculturation process has supplanted mother-tongue



language pain descriptors and that people both perceive and express their pain in ways prescribed by the 'host' culture. An alternative explanation is that sensations of pain are similar across cultures and that similar words are used to describe certain types of pain in different languages, although the study on Bangladeshi myocardial infarction patients (Barakat et al. 2003) showed that Bangladeshis were more likely than whites to use non-classical pain descriptors such as 'stabbing' 'burning' or 'sharp', rather than the classical 'tightness' 'heaviness' 'bank-like' 'weight' 'pressure' 'constricting' or 'heavy'. Bangladeshis were also more likely than white patients to report their chest pain was located less centrally and hence atypically. However, these differences may reflect genuine biological differences between South Asian and European patients, as it is possible that between-group differences in co-morbidity with conditions such as diabetes lead to the differences in MI symptom presentation.

Chinese participants were much less likely than Pakistanis to use any English terms in their speech. The elderly Chinese in Edinburgh constitute a group distinct from the wider population; they have very low fluency in English and tend to live and socialise with other Chinese people, and it is unlikely that they are fully acculturated or integrated with the majority society. This has been reported to be the case for other Chinese communities in Britain (Fong & Watt 1994).

#### **8.4 Problems with existing RAQ versions**

This study set out to assess whether versions of the RAQ in Punjabi, Cantonese and English are equally appropriate, acceptable and relevant to lay people from each

linguistic group. A number of problems were uncovered that would affect linguistic equivalence and comparability of data. This section will discuss the barriers to linguistic equivalence found: variation in meaning of specific words due to inappropriate translation (8.4.1); variations in the understandings of terms and question intent both between and within groups (8.4.2); variations in the wording and structure of questionnaire items, and the form of the questionnaire used, across languages (8.4.3); and the difficulties of ensuring equivalence when there is no written form of a language, such as Cantonese (8.4.4). Where appropriate, recommendations will be made for improvement of the RAQ in these languages to increase cross-cultural comparability. It may be feasible to produce cross-culturally valid versions of the RAQ that will yield more robust epidemiological data. To do so, the differences between questionnaire versions found in this study must be rectified and modified versions tested for improved interpretation and response (see 8.6).

#### **8.4.1 Variation in meaning of specific words due to inappropriate translation**

As mentioned above in section 8.2.1, the Punjabi and Cantonese translations of the RAQ used in this study were those developed by the Newcastle Heart Project, one of the surveys following best practice with regard to cross-cultural adaptation (as shown in 2.7, table 2.5). As illustrated in chapter 6, it was found that there is a need to modify these translations of the RAQ to improve equivalence. Both the Punjabi and the Cantonese translations of the RAQ differed in key areas from each other and from the English version and appear inadequate for comparable cross-cultural research.

Key words such as 'chest' and 'uphill' were interpreted differently across linguistic groups, producing artefactual RAQ responses in this sample and indicating that angina prevalence data previously obtained using these translations in epidemiological studies may be inaccurate. For example, both Punjabi and Cantonese versions may yield false positive cases of both angina and myocardial infarction due to women interpreting questions about pain in their chest as referring to pain in their breasts. In one case, a Pakistani woman thought that severe pain across the front of the chest (the symptom queried in the screening question for myocardial infarction) referred to pain in the nipples, and a Chinese woman thought that the initial RAQ question was asking about breast cancer. CHD prevalence rates using these translations of the RAQ must therefore be viewed with caution.

Evidence from this study suggests that the word used for 'chest', *chatti*, be replaced by the less ambiguous word *seena* in the Punjabi version of the RAQ, and that *hung*

*bo*, the translation for 'chest' in the Cantonese version, be replaced by *sum hau*. *Tay bo*, the translation used for 'uphill', which more accurately means 'walking the slope', should be replaced by '*sheung au*'. It is possible that further suggestions for better alternatives to the Punjabi translation of 'uphill', *chorai*, would have been made had the project workers probed this phrase more rigorously.

The phrase 'front of chest', translated as *morla* in the Punjabi version, was objected to by a number of Pakistani participants, most notably the women, who suggested this was a Sikh Punjabi word rather than being appropriate to Pakistani Punjabi speakers (6.2.11). They suggested the term *agla* replace *morla*. The Pakistani men objected to *morla* much less than the women. Whether this discrepancy between male and female Pakistanis is due to a genuine variation in understanding, a reduced tendency in the men to express disagreement with the translation due to personality propensities or interview technique, or whether the male Punjabi project worker simply did not use the NHP translation of *morla* is unclear. Similarly, the translation for 'on the level', *padhry*, was objected to on the same basis.

There are regional variations in Punjabi that will complicate the administration of Punjabi questionnaires. It may be necessary to specify whether a Punjabi questionnaire is suitable for Pakistani or Indian respondents, or to ensure field-testing in each of these groups to ascertain appropriateness. For example, it is possible that Indian Punjabis would not understand the Pakistanis' suggestion of *agla* for 'front of chest'. In addition, the Punjabi spoken in Britain may be different from that spoken in India or Pakistan. British Punjabi may represent the Punjabi spoken in the era of

the first wave of immigration, rather than current sub-continental Punjabi that has evolved to include modern turns of phrase and which incorporates Hindi and Urdu influences. It is important for researchers to try and use terms that all of the target population would understand. However, researchers may have to accept that some languages have too many regional variations or dialects to ensure understanding of a standard questionnaire in the whole population, and this may prove a barrier to the standardised administration of questions that epidemiology ideally requires. Even if the majority of a population can understand a questionnaire, it may be that, for example, an elderly Cantonese speaker speaks a specific regional dialect and lacks understanding of a particular word or phrase. In the case of the RAQ, as noted in 2.7, Rose cautioned that questions must be put to the respondent exactly as stated, as even minor variation in wording could lead to 'unexpectedly large differences' (Rose 1962, p.650). Overcoming the obstacle of small numbers of respondents speaking relatively obscure regional dialects depends on two factors. Firstly, the interviewee would need to be sufficiently comfortable with the interview to communicate to the person administering the questionnaire that they did not understand a particular word or phrase; this may not be likely if doing so would lead to embarrassment or loss of face. Secondly, the interviewer would need to paraphrase the question in a manner that the interviewee would understand, a process that risks loss of standardisation. Carrying out qualitative research within the target population to investigate understandability of terms and discussing standardised explanations with interviewers prior to survey work may be a way to increase epidemiological rigour by taking steps to ensure equivalence of meaning across interviews.

By replacing the Newcastle Heart Project translations of the terms outlined above with the alternatives suggested by participants, the modified versions of the RAQ in Punjabi and Cantonese will be more acceptable, have greater face validity and potentially greater comparability with each other and the English, and may yield more accurate data about the prevalence of angina in these populations. To establish improved cross-cultural validity, however, modified questionnaires would need to be tested on a larger population sample for other types of validity (see 8.6) and reliability (the degree to which the results can be replicated) and further modifications made as necessary, as reviewed in chapter 3.4.3.

#### **8.4.2 Variation in understanding of terms and question intent between and within groups**

Some terms used in the different language versions of the RAQ did not seem to be inappropriately translated, but the understanding of these terms tended to vary both between and within groups. For some terms, such as 'pain', *dard* (Punjabi) and *tung* (Cantonese), whilst there was some variation in the understanding of these terms, generally the meanings were similar. 'Discomfort', *takleef* (Punjabi) and *ng su fo* (Cantonese) may have similar meanings in relation to physical discomfort, but *takleef* and *ng su fo* were also thought to have a psychosocial dimension that the English-speakers did not express in relation to the term 'discomfort'. There was also some inconsistency in articulating the difference between, for example, *dard* and *takleef*. Sometimes *dard* was seen as more severe than *takleef*, sometimes *vice versa*. It may be that some variation in understanding is due to participants' difficulty in articulating their understanding of common terms. Participants may not have



considered the meaning of 'pain' before and their responses may be an initial reaction. It is possible that, if given more time to consider and discuss the meaning of terms such as 'pain' and 'discomfort', participants might have presented a more consistent picture of the differences between these two terms. On the contrary, as one project worker mentioned (6.2.1), it may be difficult for lay people to express the difference between these terms. However, the RAQ does ask whether the respondent has ever experienced pain or discomfort; the inclusion of both terms may mean that variation between respondents about which is the more severe condition does not matter. In addition, as mentioned in section 8.2.2.4 above, it is important to note that a project worker's misunderstanding of the study may have affected the data generated. For example, one of the Punjabi speaking project workers began by querying participants' understandings of the English terms, 'pain' and 'discomfort', rather than the Punjabi translations.

The psychosocial dimension to the Punjabi and Cantonese translations for 'discomfort' may not necessarily undermine comparability with the English version, or subvert the intended meaning of the question, as Pakistani and Chinese participants attributed the initial question to be asking about a physical condition, and many were able to identify the intention of the question to be refer to cardiac pain. However, no participants misinterpreted the first RAQ question as relating to psychological distress. As noted in 3.7.4 and 8.3.2, Indian Punjabi speakers have been shown to use a metaphor of a 'sinking heart' to communicate psychological distress (Krause 1989); in English the 'heart' is used commonly in various phrases such as 'heartbroken' or 'heartache' to represent psychological suffering; and a

single Chinese participant in this study used the phrase *sum ng su fo* [heart discomfort] (6.2.1) to express psychological pain. It is perhaps surprising that more participants from all groups did not use these metaphors in their interviews. Although, as stated previously, there was no evidence from this study's examination of the first RAQ question that pain or discomfort in the chest was being interpreted in any way other than as a physical sensation, one Chinese woman did interpret the subsequent screening question for myocardial infarction (severe pain across the front of the chest lasting for half an hour or more) as querying psychological pain and unhappiness. This misinterpretation would lead to artefactual results in an epidemiological survey if more of the Chinese population also interpreted the question in this way.

Another finding that may affect RAQ performance within rather than between groups is variation in individual understanding of the area covered by the words 'chest', *chatti* (Punjabi) and *hung bo* (Chinese). In addition to the interpretation by some ethnic minority women that these translations referred to their breasts, there was much variation in the body area thought to be covered by these terms. Variations between cultural and language groups in the anatomical area covered by the word 'chest' have been reported previously; for example, Gujaratis have been shown to translate the English term 'ribs' into the Gujarati term for 'chest' (Ebden et al. 1998). Whilst the understanding of the area covered by 'chest' did not vary systematically between groups in this case study, it may lead to a decrease in performance of the RAQ in all groups. For example, if a respondent considers his or her chest to include the area just above the waist (6.2.1), exertional pain in this area might be reported



that is not angina. This possibility is corroborated further by some Chinese participants' opinion that this question related to a problem with their kidneys, liver or stomach (6.2.1). These findings indicate that the symptoms of 'chest pain' in different languages may be attributed to a variety of causes. However, the RAQ should, overall, be able to distinguish between these cases and those of genuine angina by the sequence of questions becoming more specific, including the stipulation that angina is only present if it is relieved within ten minutes by rest and is situated in the sternum or left arm (see chapter 2.4). One of the latter RAQ questions asks participants to show the interviewer on a diagram where 'it', the pain, was located. However, the cross-cultural validity of the RAQ assumes that angina manifests a similar symptom profile in different ethnic groups. It has, however, been shown that angina patients in some ethnic groups report a more diffuse chest pain than the classical symptoms (Fischbacher et al. 2001). After face and content validity is investigated by qualitative investigations with the lay populations as in this study, further work needs to be carried out on the clinical aspects of angina in different ethnic groups and gender sub-groups, in order to clarify whether the RAQ is suitable for epidemiological use in these groups.

Some participants pointed out that there was much individual variation in understanding of phrases like 'hurry' and 'ordinary pace' (6.2.4). Whether this is important in influencing validity of RAQ responses within or between groups requires further investigation. This study did not suggest that there were systematic between-group differences in the understandings of these phrases. However, individuals from all groups may vary considerably in the likelihood of hurrying or

walking uphill, and this might affect the likelihood of experiencing symptoms of angina. In addition, the methods used may have affected these results. As described in section 8.2.2.4 above, there was much variation between interviewers and between interviews in the probing of the meaning of certain terms. For example, as aforementioned, 'ordinary pace' was probed in a small minority of Punjabi interviews, therefore making it difficult to assess equivalence of meaning across groups studied.

There was also some variation in overall understanding of certain items; for example, some Cantonese speakers interpreted the additional RAQ question "Did you see a doctor because of this pain?" to be referring to general pain rather than pain or discomfort in the chest. Whilst not appearing to be a function of an inappropriate translation or a cultural theme, this misunderstanding clearly undermines the question's validity in the individual cases where this interpretation occurred as it would lead to an inappropriate response.

#### ***8.4.3 Variations in the wording of items and the form of the questionnaire across languages***

The differing forms of the RAQ used in the NHP can be explained by the design of that study. The South Asian and Chinese phases of the NHP did not take place simultaneously, and different teams of staff worked on each phase. Chinese participants were screened in 1991-1993 (Harland et al. 1997), Europeans in 1993-1994 and South Asians in 1995-1997 (Bhopal et al. 1999).

Rose Angina Questionnaire questions were asked in different ways across groups, undermining comparability between cultures. For example, the Chinese translation for the 'symptom' appeared in the Chinese version of the questionnaire, but not in the English or Punjabi versions. After the initial question "Have you ever had pain or discomfort in your chest?", the subsequent questions in the Chinese version could be translated as "Do you get this symptom when you walk uphill or hurry?" and "Do you get this symptom when walking at an ordinary pace on the level?"

Consequently, some Cantonese participants interpreted the questions to refer to breathlessness (6.2.3), not pain or discomfort in the chest, due to the use of the word 'symptom'. This may also indicate that the original phrase, "Have you ever had pain or discomfort in the chest?" connoted breathlessness for this group, and might lead to a mistaken diagnosis of angina.

In addition, different forms of the RAQ were used in different languages, also undermining comparability. For example, the Chinese version included an extra question after the initial question "Have you ever had pain or discomfort in your chest?". The extra question asked "If no, have you ever had any pressure or heaviness in your chest?" (6.2.2). The absence of this question in the other languages meant there could be no comparison of responses between groups. In addition, the item itself was confusing to Chinese participants and of doubtful validity in this language group; furthermore, it undermined the validity of subsequent questions.

Firstly, the translation was inappropriate for use in a lay Cantonese-speaking population; some participants didn't understand the translation used for 'heaviness', *cheung lek*. Secondly, some respondents interpreted 'pressure' to be psychological pressure rather than a physical sensation. Thirdly, others interpreted the question to relate to an external object pressing on their chest. These three factors contribute to this item being invalid for use in its current state. However, in addition, the inclusion of this item in the Chinese questionnaire also affected understanding of subsequent questions. As outlined in the results (6.2.3 & 6.2.4) and discussed above, subsequent questions in the Cantonese version use the words 'the symptom' rather than specifying 'pain or discomfort in the chest'. By including this question on pressure and heaviness, some participants interpreted the 'symptom' to refer to the 'pressure and heaviness' in the preceding question, rather than chest pain. This reduces the comparability of different language versions further, as the Punjabi and English versions contain no item referring to pressure or heaviness.

To increase comparability of Punjabi, Cantonese and English versions of the RAQ, each should include the same set of questions and ensure that they are translated in the same clear way across groups to avoid ambiguity, for example by specifying 'pain and discomfort in the chest' rather than using the terms 'symptom' or 'it'. It is therefore important for researchers to bear in mind the equivalence and comparability of questionnaires used in different phases or populations in research, and for researchers to work collaboratively to ensure consistency of methods and materials across groups and both within and between surveys. Ideally, questionnaires should be developed in parallel rather than sequentially.

#### **8.4.4 No written form of verbal Cantonese**

Whilst exact standardisation of wording is essential in epidemiological questionnaires, this could be problematic with interviewer-administered questionnaires in non-English languages. For example, one problem in maintaining standard administration is the fact that oral Cantonese has no written equivalent. Hence, Cantonese speaking interviewers may vary in their translation of the written Chinese, potentially leading to significant distortion of results. An alternative to relying on interviewers' spot translations may be to write the questions in phonetic Cantonese. Otherwise, if a survey is small, a single interviewer could be employed to administer the questionnaires and instructed to use the same oral Cantonese in each interview. Alternatively, a team of interviewers could be strictly trained in standardised oral Cantonese administration of the questions- a process that would depend on their accurate recall of Cantonese items if no phonetic written version was made. Another alternative may be to pre-record the Cantonese questions onto tape, which the person administering the questionnaire could then play to the respondent.

#### **8.5 Factors influencing questionnaire response tendencies**

This study also assessed whether people from different cultural groups tended to respond to the RAQ questions and the mode of administration in similar ways. It was proposed that experience of, and attitudes to, this type of enquiry may influence readiness of response to a questionnaire (see 3.4.2). It was found that questionnaire response tendencies might be more likely to vary by individual's experience and personality rather than by cultural group.

### **8.5.1 Attitudes to/ experience of questionnaires**

As shown in 7.2, all groups showed similar awareness and experience of questionnaires; however, attitudes towards questionnaires ranged across all groups from positive to negative. Few participants had experience of taking part in a health survey or filling out questionnaires. Most participants said that they would assess the worth of the questionnaire before agreeing to take part. Amongst the Chinese, a factor in their consideration of a questionnaire would be whether or not they could read it or obtain someone to read and explain it to them, as literacy in both English and Chinese languages was low. This might affect the readiness with which people agree to take part and has implications for the ease of survey questionnaire administration, as interviewer-administered versions would be necessary. As reviewed in chapter 2.5, the mode of administration of the RAQ, whether self-completed or interviewer-administered, has been shown to affect the prevalence of angina yielded. Researchers should bear in mind the non-comparability of different modes of administration; ideally, the manner of eliciting responses to the questionnaire should not vary by ethnic group. If so, this might lead to variations in angina prevalence between groups that were functions of the mode of administration rather than reflecting genuine differences in disease status between groups. However, this is not usually possible practically due to resource restrictions; the cost of an interview-administered survey is much higher than a self-completed one. In groups where it is possible that some participants may be able to respond by self-completion and others require an interview-administered form of the survey, the

results could be analysed to check for systematic bias between modes of administration.

### **8.5.2 *Attitudes to taking part in research***

Overall, the finding from all groups (chapter 7.4) was that participation in this research study, and hence research in general, may depend to some extent on who is 'doing the asking'. Some English speaking volunteers, recruited via letter from their GP, had agreed to take part because of a sense of obligation to their doctor; some ethnic minority participants, recruited via personal contact by a member of their own community, had agreed to take part because of a sense of social obligation.

However, other participants from all groups appeared keen to be involved in research for a range of reasons, including general interest, health-related concerns, or altruism. The Punjabi men, in particular, were very positive about taking part in this research, showing interest and support and seeming to see a clear correlation between taking part and increasing awareness of health with positive outcome, and assisting their community. This may have ramifications for participation in larger-scale health surveys. There may be a stronger sense of empowered community or social obligation in the Pakistani group than in the others. Another explanation for this finding may be that the project workers probed this option in different ways across groups. It may be that Pakistani participants are more likely to take part in surveys about health, particularly, as suggested in 8.2.2.1, if asked to do so by someone from their own community. However, these statements of support for the community and



willingness to participate in health surveys may also have been a socially acceptable response made in the presence of the Pakistani project worker.

### **8.5.3 Health-care seeking behaviour and attitudes**

It was noted in 3.7.6 that some ethnic groups were more likely to report angina if they felt that they were not getting needed medical care (Smith et al. 1993).

Participants in this study were asked about their frequency of consulting their GP, and attitudes to the health care they had received (results presented in 7.3). A range of consultation behaviour was reported across all groups in this case study. Previous work has suggested that, whilst people from some ethnic minorities, particularly South Asians, show high GP consultation rates compared to the majority population (Balarajan & Raleigh 1989), other work has shown that Chinese people in Glasgow consult their GP significantly less often than the white population (Liao & McIlwaine 1995), and that service utilisation in relation to need is low amongst some of these groups, particularly the Chinese and some Pakistani women (although high for the Pakistani population as a whole) (Smaje & Le Grand 1997). Amongst those participants who said they did not often consult their doctor, the interviewers did not often probe why this was the case. However, most of these participants proceeded to state that they were satisfied with their care so it may be unlikely in the majority of cases that they do not attend a GP surgery due to perceived difficulties in doing so, or reluctance to do so. It is possible that some participants were reluctant to criticise the medical profession, and that these interviews were accessing 'public' as opposed to 'private' accounts. Alternatively, rather than indicating a preference for respecting the medical profession generally, a positive statement about satisfaction with care



may represent a more general reluctance to be negative or critical about life events; or may be an interview phenomenon due to participants' tendencies to respond positively because of fatigue, deference, disinterest or lack of understanding.

Previous research has reported that Chinese people delayed using Western medicine in favour of using Chinese medicine (Facione, Giancarlo, & Chan 2000), and that traditional beliefs can affect interaction with the Western health care systems (Fong & Watt 1994). These findings were not replicated amongst the participants interviewed in this study. Cantonese speaking participants reported no particular reluctance to consult their Western GP and no pronounced preference for Chinese medicine practitioners. Their use was mentioned in some cases, but rarely as a precursor to consulting a Western doctor. Research amongst Hong Kong Chinese reported similar results: participants were often familiar with biomedical concepts and were willing to use Western medicine for symptom relief or prevention where appropriate, whilst traditional health practices played a supplementary role (Koo 1987). A similar finding has been reported in South Asians in the UK (Bhopal 1986c).

The minority of participants who spoke critically of the health services was present in all three groups. A few of Pakistani men expressed some concerns about racism in the health services and dissatisfaction with care, but overall participants from all three groups spoke quite positively about their experiences with doctors. Previous research supports this finding; it has been shown that Pakistani patients in Middlesbrough report high satisfaction with national health services (Madhok, Hameed, & Bhopal 1998), and that Chinese patients in Glasgow were mostly

satisfied with the services provided by their GP (Liao & McIlwaine 1995) .

However, another study comparing white, South Asian, black and Chinese patients' assessments of primary care in London reported that the ethnic minority participants assessed the services significantly less favourably than white patients did (Campbell, Ramsay, & Green 2001).

Overall, this study does not indicate that any particular group would be more likely than any other to report angina due to a perceived deficit in medical care.

### **8.6 Suggestions for postdoctoral research based on this case study**

There was evidence that there was scope for improvement of Punjabi and Cantonese versions of the Rose Angina Questionnaire. Their cross-cultural comparability should be addressed further using both qualitative and quantitative techniques.

The next step in the process of establishing cross-culturally valid versions of the RAQ in Punjabi and Cantonese would be to produce modified versions that incorporate lay people's suggestions from this study and eliminate any questions, such as RAQ 1b, that were not used in all groups. Once modified, these versions could be tested further on larger samples for validity and repeatability.

Ideally, the RAQ should be tested for face, content and criterion validity, repeatability and responsiveness to change. This study has taken steps towards improving face and content validity. As defined in chapter 2.7, face validity refers to whether the questionnaire items are clear and unambiguous; content validity refers to

whether the questionnaire content accurately reflects the phenomenon under study (Bowling 2000). Criterion validity, defined in 2.6, refers to the extent to which a measurement or instrument outcome correlates with an external measure of the phenomenon under study (ed. Last 1995). Repeatability, as stated in 2.5, refers to the extent to which the results are closely similar each time the instrument is administered (ed. Last 1995). Responsiveness to change refers to the association between a change in the questionnaire outcome and a change in the true value of a construct (Bowling 2000).

However, as there is no 'gold standard' for establishing angina at this time, the process of establishing criterion validity and responsiveness to change may be problematic, particularly in a cross-cultural setting. One criterion that has been used to assess the performance of the RAQ is its correlation with a doctor's diagnosis of angina and with Q-waves on ECG (Fischbacher et al. 2001). Q-waves are indicative of a previous myocardial infarction, and as such are thought to be likely to correlate with the presence of angina. Alternatively, criterion validity could be assessed by correlating response to the RAQ with eventual fatality in a longitudinal study (Owen-Smith, Hannaford, & Elliot 2003).

The use of criteria such as these may be flawed for the establishment of RAQ performance in different ethnic groups, as the criteria themselves may have differing cross-cultural validity. Little is known about whether the spectrum of the disease is similar in different ethnic groups and, therefore, whether people from different groups are equally likely to experience angina if they have had a previous myocardial

infarction (as shown by Q-waves on electrocardiograph); or whether there is a similar relationship between mortality and the experience of angina across groups. In addition, there are no longitudinal studies on the health of Britain's ethnic minorities available at present to investigate the relationship between mortality and reported angina. Similarly, a doctor's diagnosis of angina may only select a sub-set of individuals from a particular ethnic group who express themselves in accordance with a medical professional's classical understanding of angina based on Western patients.

Testing for responsiveness to change would involve investigating the RAQ response in individuals before and after they had received treatment to reduce the symptoms of their angina (such as beta-blockers), and ensuring that the RAQ outcome reflected that change in a population. However, people of different ethnicities may respond to treatment in different ways and reduction of symptoms may vary. Also, angina may be undiagnosed in people who express non-classical symptoms, and who therefore would not be prescribed treatment; it would be impossible to establish responsiveness to change in this population. In addition, the RAQ question "Have you ever had any pain or discomfort in your chest?" is in the past tense, whilst subsequent questions querying exertional chest pain are in the present tense. This may confuse respondents, who may not understand whether the questionnaire is assessing distant past or relatively current symptoms. Establishing responsiveness to change of the RAQ would depend on two measures of current angina status.

Lack of a 'gold standard' of the construct being measured is not unusual in survey research; for example, questionnaires on quality of life, patient-assessed outcomes, and satisfaction with care. When this is the case, the types of validity testing outlined above can provide only an indication of performance. However, it may be feasible only to establish face and content validity and repeatability. Given the problems in the criteria used to assess RAQ performance outlined above, the best option for further work may be to concentrate further on ensuring the cultural, linguistic, and functional equivalence of the modified versions of RAQ suggested by this research. Subsequent research could therefore investigate face and content validity of the RAQ in a larger sample of the population under study. In addition, further investigation into the face and content validity of the English-speaking version in larger samples is necessary to ensure the questions are not ambiguous and that the content of the questionnaire is an accurate reflection of the population's experience of angina. Respondents from all groups could be asked to answer the RAQ and the pattern of response analysed to assess missing or suspect data, which may indicate problems in interpretation of items.

It should also be possible to establish the reliability of the modified versions of the RAQ. The 'new' versions could be administered to a group of Pakistani Punjabi or Chinese Cantonese speakers on two separate occasions. An appropriate length of time would need to be left between administering the different versions to the same individuals: short enough to ensure that the likelihood of angina developing within that time was low, and long enough to allow the participants some distance from the original task.

To address the issue of inter-interviewer bias when using the modified RAQ versions in future surveys, it would be valuable to research the possibility of developing an interactive computer or video programme to ease the delivery of standardised questions. A less sophisticated approach may be to audiotape the standard questions and caution interviewers not to elaborate or discuss the questions.

It may be that similar problems to those found in the translations of the RAQ investigated in this study also exist in the numerous other surveys using the RAQ in non-English speaking populations (see chapter 2.7). The majority of the studies reviewed gave no details of the translation process, and they may have been even less rigorous than the Newcastle Heart Project's forward and back translation, followed by conferring between translators. The work carried out in this study should, therefore, be repeated for other language versions of the RAQ, both within Britain and internationally, to ensure that key translation errors are not present.

The methods and insights developed from this study could also be applied to further cross-cultural validation work on other questionnaires, which may also have been inappropriately translated or adapted for use in non-English speaking cultures. As reviewed, previous work has also shown problems with translations of tobacco and alcohol questionnaires in national surveys in Britain (Bhopal et al. 2004). Currently, research is being carried out by the author, in conjunction with Professor Raj Bhopal and Dr. Sonja Hunt at Public Health Sciences, University of Edinburgh, entitled "The use of tobacco and related substances in ethnic minorities: the development of a

culturally valid measure." The project is funded by Partnership Action on Tobacco and Health, and aims to take steps towards developing a comprehensive tobacco-related questionnaire in Punjabi, Urdu, Cantonese and Sylheti for use in Scottish national surveys. The work has been informed by, and builds upon, the findings and techniques explored in this Ph.D. project.

Further work could also involve the lay communities in assessing the acceptability and understandability of other types of translated materials in addition to questionnaires, such as health promotion materials or patient information sheets, where a similar translation problems to those found in the RAQ and other questionnaires may apply.

## **8.7 Conclusions and recommendations**

This thesis has investigated the challenge of cross-cultural comparability in survey research, using the Rose Angina Questionnaire as a case study. Steps were taken to assess the feasibility of establishing conceptual, lexical and functional equivalence (as defined in 3.4.1) of the RAQ in three ethnic groups. A number of insights into cross-cultural comparability of questionnaires, and recommendations for carrying out research on this topic, have been made throughout this thesis. Five key messages have been chosen as meriting emphasis.

First, despite the limitations of the methods used in this case study, several problems were found in the translations of the RAQ used by the Newcastle Heart Project. It is possible to state that the Punjabi, Cantonese and English versions of the RAQ used in



the Newcastle Heart Project were not equivalent. This study has illustrated the importance of questioning assumptions common in epidemiology, such as the translation of survey instruments being a relatively straightforward part of the methodology. It could be assumed that the RAQ would be an easy questionnaire to translate; it is short and appears simple, based mainly on physical symptomatology and does not touch on any constructs that may be more obviously culturally determined, such as mental health. However, despite the apparent simplicity of the questionnaire, this study uncovered a relatively large number of important translation and adaptation errors that render the versions studied incomparable. This lack of cross-cultural comparability was probably due to a failure to involve monolingual lay people in the cross-cultural adaptation process. Researchers should be conscious that translation is not a simple, error-free process and should be rigorous in ensuring comparability of different language versions of survey questionnaires they use. Close collaboration with translators should be ensured to discuss cultural appropriateness and the intent of each questionnaire item. Whilst a close debate between researchers and translators to ensure conceptual equivalence has been recommended in the sociological literature (Temple 1997), greater awareness of this issue is required in biomedical research.

Second, whilst it is not possible to make any statements about the generalisability of the health-related beliefs and attitudes that might affect RAQ response uncovered throughout this study, the issues raised- such as varying understanding of angina, tendency to minimise health problems, or understanding of questionnaires- are points



of interest that may apply to the wider population and should therefore be borne in mind when carrying out cross-cultural research.

Third, other studies reporting angina in different language groups should be viewed with caution, prior to further work being carried out to ensure their cross-cultural validity. It may be that other versions of the RAQ are even less comparable to the English or to each other than the ones investigated in this thesis due to less than adequate translation methods. Therefore, care should be taken before accepting the accuracy of the angina prevalence yielded by these studies, or before comparing prevalence between studies internationally. Similarly, other questionnaires used in survey research across a range of disciplines may be reporting artefactual data if their cross-cultural adaptation methodology is inadequate and did not involve assessing lay people's understanding of questionnaires.

Fourth, a questionnaire assessment task by lay people is theoretically desirable but practically challenging. The task should be clarified for participants by explaining that questionnaires sometimes use the type of language that people from their community do not understand and that they are being consulted in order to make better questionnaires for people who speak their language. In addition, bilingual project workers should be selected on the basis of their ability to understand a questionnaire assessment task and to carry it out in a standardised manner, and should be rigorously trained to ensure they do so.

Finally, working through previously untrained bilingual project workers can lead to inadequate control of the quality of data generated. Ideally, a research team overseeing an investigation into the cross-cultural comparability of questionnaires, or a qualitative study in a range of languages, should include academic researchers bilingual in the relevant languages to facilitate collection of high quality interview data by community project workers. More bilingual people from a range of ethnic groups should be encouraged to enter the field of theoretical and applied research.

In conclusion, it is important to note that public health research aims and methods must be responsive to, and appropriate for, today's multiethnic Britain. This case study has contributed to the advancement of robust cross-cultural research.

## References

- Abernathy, J. R., Thorn, M. D., Trobaugh, G. B., Ekelund, L.-G., Maciolowski, M., Lupovetsky, B., Shelnova, M. D., Zhukovsky, M. D., Shestov, D., & Deev, A. 1988, "Prevalence of ischemic resting and stress electrocardiographic abnormalities and angina among 40 to 59 year old men in selected U.S. and U.S.S.R. populations", *Circulation*, vol. 77, pp. 270-278.
- Abramson, J. H. & Abramson, Z. H. 1999, *Survey methods in community medicine*, 5th edn, Churchill Livingstone.
- Ahern, K. J. 1999, "Pearls, pith and provocation: ten tips for reflexive bracketing", *Qualitative Health Research*, vol. 9, no. 3, pp. 407-411.
- Allison, T. R., Symmons, D. P. M., Brammah, T., Haynes, P., Rogers, A., Roxby, M., & Urwin, M. 2002, "Musculoskeletal pain is more generalised among people from ethnic minorities than among white people in Greater Manchester", *Annals of the Rheumatic Diseases*, vol. 61, pp. 151-156.
- Andersen, L. I., Madsen, P. V., Dalgaard, P., & Jensen, G. 1987, "Validity of clinical symptoms in benign esophageal disease, assessed by questionnaire", *Acta Medica Scandinavia*, vol. 221, no. 2, pp. 171-177.
- Angel, R. & Guarnaccia, P. J. 1989, "Mind, body and culture: somatization among Hispanics", *Social Science and Medicine*, vol. 28, no. 12, pp. 1229-1238.
- Appels, A. 1997, "Depression and coronary heart disease: observations and questions", *Journal of Psychosomatic Research*, vol. 43, no. 5, pp. 443-452.
- Ashcroft, M. T. 1976, "Problems in interpreting electrocardiograms (ECGs) and questionnaires for effort pain in rural Jamaica", *West Indian Medical Journal*, vol. 25, pp. 216-225.
- Aspinall, P. J. 1997, "The conceptual basis of ethnic group terminology and classifications", *Social Science and Medicine*, vol. 45, pp. 689-698.
- Aspinall, P. J. 1998, "Describing the "white" ethnic group and its composition in medical research", *Social Science and Medicine*, vol. 47, pp. 1797-1808.
- Atkinson, P., Batchelor, C., Bloor, M., & Owens, D. 1994, *The advantages and disadvantages of qualitative methods for studying health beliefs and barriers in South Asian communities*, Health and Personal Social Services Research Group, School of Social and Administrative Studies, University of Wales, Cardiff.
- Bailey, N., Bowes, A. M., & Sim, D. F. 1997, "The demography of minority ethnic groups in Scotland," in *Perspectives on welfare*, A. M. Bowes & D. F. Sim, eds., Aldershot, Ashgate.

- Balarajan, R. 1991, "Ethnic differences in mortality from ischaemic heart disease and cerebrovascular disease in England and Wales", *British Medical Journal*, vol. 302, pp. 560-564.
- Balarajan, R. 1996, "Ethnicity and variations in mortality from coronary heart disease", *Health Trends*, vol. 28, pp. 45-51.
- Balarajan, R. & Raleigh, V. 1989, "Ethnic differences in general practitioner consultations", *British Medical Journal*, vol. 299, pp. 958-960.
- Barakat, K., Wells, Z., Ramdhany, S., Mills, P. G., & Timmis, A. D. 2003, "Bangladeshi patients present with non-classic features of acute myocardial infarction and are treated less aggressively in east London, UK", *Heart*, vol. 89, pp. 276-279.
- Barker, D. J. 1995, "Fetal origins of coronary heart disease", *British Medical Journal*, vol. 311, pp. 171-174.
- Bass, E. B., Follansbee, W. P., & Orchard, T. J. 1989, "Comparison of a supplemented Rose Questionnaire to exercise thallium testing in men and women", *Journal of Clinical Epidemiology*, vol. 42, no. 5, pp. 385-394.
- Bates, M. S. & Edwards, W. T. E. 1992, "Ethnic variations in the chronic pain experience", *Ethnicity and Disease*, vol. 2, pp. 63-83.
- Beishon, S. & Nazroo, J. Y. 1997, *Coronary heart disease, construing the health beliefs and behaviours of South Asian communities*, Health Education Authority, London.
- Berkanovic, E. 1980, "The effect of inadequate language translation on Hispanics' responses to health surveys", *American Journal of Public Health*, vol. 70, pp. 1273-1281.
- Berry, J. W. 1969, "On cross-cultural comparability", *International Journal of Psychology*, vol. 4, no. 2, pp. 119-128.
- Berry, J. W. 1989, "Imposed etics-emics-derived etics: the operationalization of a compelling idea", *International Journal of Psychology*, vol. 24, pp. 721-735.
- Bhopal, R. 1991, "Health education and ethnic minorities", *British Medical Journal*, vol. 302, p. 1338.
- Bhopal, R. 2002a, *Concepts of epidemiology*, Oxford University Press, Oxford.
- Bhopal, R. 2002b, "Epidemic of cardiovascular disease in South Asians", *British Medical Journal*, vol. 324, pp. 625-626.
- Bhopal, R., Phillimore, P., & Kohli, H. S. 1991, "Inappropriate use of the term 'Asian': an obstacle to ethnicity and health research", *Journal of Public Health Medicine*, vol. 13, pp. 244-246.

Bhopal, R., Unwin, N., White, M., Yallop, J., Walker, L., Alberti, K. G., Harland, J., Patel, S., Ahmad, N., Turner, C., Watson, B., Kaur, D., Kulkarni, A., Laker, M., & Tavridou, A. 1999, "Heterogeneity of coronary heart disease risk factors in Indian, Pakistani, Bangladeshi and European origin populations: cross-sectional study", *British Medical Journal*, vol. 319, pp. 215-220.

Bhopal, R., Vettini, A., Hunt, S., Wiebe, S., Hanna, L., & Amos, A. 2004, "Review of prevalence data in, and evaluation of cross-cultural methods for cross-cultural adaptation of, surveys on tobacco and alcohol in ethnic minority groups", *British Medical Journal*, vol. 328, no. 7431, p. 76.

Bhopal, R. S. 1986a, "Asian's knowledge and behaviour on preventive health issues: smoking, alcohol, heart disease, pregnancy, rickets, malaria prophylaxis and *surma*", *Community Medicine*, vol. 8, no. 4, pp. 315-321.

Bhopal, R. S. 1986b, "Bhaye Bhaddi: a food and health concept of Punjabi Asians", *Social Science and Medicine*, vol. 23, no. 7, pp. 687-688.

Bhopal, R. S. 1986c, "The inter-relationship of folk, traditional and Western medicine within an Asian community in Britain", *Social Science and Medicine*, vol. 22, no. 1, pp. 99-105.

Bhui, K. & Bhugra, D. 2001, "Transcultural psychiatry: some social and epidemiological research issues", *International Journal of Social Psychiatry*, vol. 47, no. 3, pp. 1-9.

Bjartveit, K., Foss, O. P., & Gjervig, T. 1983, "The cardiovascular disease study in Norwegian counties. Results from first screening", *Acta Medica Scandinavica Supplement*, vol. 675, pp. 1-184.

Bollini, P. & Siem, H. 1995, "No real progress towards equity: health of migrants and ethnic minorities on the eve of the year 2000", *Social Science and Medicine*, vol. 41, pp. 819-828.

Bowling, A. 2000, *Research methods in health*, Open University Press, Buckingham.

Bowman, K. W. & Hui, E. C. 2000, "Bioethics for clinicians: 20. Chinese bioethics", *Canadian Medical Association Journal*, vol. 28, no. 163, pp. 11-1481.

Britten, N. 1995, "Qualitative interviews in medical research", *British Medical Journal*, vol. 311, pp. 251-253.

Bullinger, M., Alonso, J., Apolone, G., Leplege, A., Sullivan, M., Wood-Dauphinee, S., Gandek, B., Wagner, A., Aaronson, N., Bech, P., Fukuhara, S., Kaasa, S., & Ware, J. 1998, "Translating health status questionnaires and evaluating their quality: The IQOLA project approach", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 913-923.

- Bullinger, M., Anderson, R., Cella, D., & Aaronson, N. 1993, "Developing and evaluating cross-cultural instruments from minimum requirements to optimal models", *Quality of Life Research*, vol. 2, pp. 451-459.
- Bulpitt, C. J., Shipley MJ, Demirovic J, Ebi-Kryston KL, Markowe HL, & Rose G 1990, "Predicting death from coronary heart disease using a questionnaire", *International Journal of Epidemiology*, vol. 19, no. 4, pp. 899-904.
- Burr, J. 2002, "Cultural stereotypes of women from South Asian communities: mental health care professionals' explanations for patterns of suicide and depression", *Social Science and Medicine*, vol. 55, pp. 835-845.
- Bush, J., White, M., Kai, J., Rankin, J., & Bhopal, R. 2003, "Understanding influences on smoking in Bangladeshi and Pakistani adults: a community based qualitative study", *British Medical Journal*, vol. 326, no. 7396, p. 962.
- Cambridge, J. 1999, "Information loss in bilingual medical interviews through an untrained interpreter", *The Translator*, vol. 5, no. 2, pp. 201-219.
- Campbell, C. & McLean, C. 2002, "Ethnic identities, social capital and health inequalities: factors shaping African-Caribbean participation in local community networks in the UK", *Social Science and Medicine*, vol. 55, pp. 643-657.
- Campbell, J. L., Ramsay, J., & Green, J. 2001, "Age, gender, socioeconomic, and ethnic differences in patient's assessments of primary health care", *Quality in Health Care*, vol. 10, no. 2, pp. 90-95.
- Campbell, M. J., Elwood, P. C., Abbas, S., & Waters, W. E. 1984, "Chest pain in women: a study of prevalence and mortality follow-up in South Wales", *Journal of Epidemiology and Community Health*, vol. 38, pp. 17-20.
- Carr-Hill, R., Passingham, S., Wolf, A., & Kent, N. 1996, *Lost Opportunities: The language skills of linguistic minorities in England and Wales*, The Basic Skills Agency, London.
- Cederlof, R., Jonsson, E., & Lundman, T. 1966, "On the validity of mailed questionnaires in diagnosing "Angina Pectoris" and "Bronchitis"", *Archives of Environmental Health*, vol. 13, pp. 738-742.
- Chambers, J. & Bass, C. 1998, "Atypical chest pain: looking beyond the heart", *QJM- Monthly Journal of the Association of Physicians*, vol. 91, no. 3, pp. 239-244.
- Chaturvedi, N. & McKeigue, P. M. 1994, "Methods for epidemiological surveys of ethnic minority groups", *Journal of Epidemiology and Community Health*, vol. 48, no. 107, p. 111.
- Chaturvedi, N., Rai, H., & Ben-Shiomo, Y. 1997, "Lay diagnosis and health-care seeking behaviour for chest pain in south Asians and Europeans", *The Lancet*, vol. 350, no. 9091, pp. 1578-1583.



- Chen, C.-H., Chuang, J.-H., Kuo, H.-S., Chang, M.-S., Wang, S.-P., & Chou, P. 1996, "Prevalence of coronary heart disease in Kin-Chen, Kinmen", *International Journal of Cardiology*, vol. 55, pp. 87-95.
- Chung, W. Y., Wong, C. H., Yang, J. C., & Tan, P. P. 2001, "[The use of Cantonese pain descriptors among healthy young adults in Hong Kong] [Chinese]", *Acta Anaesthesiologica Sinica*, vol. 36, no. Supplement 4, pp. S1-S11.
- Chwalow, A. J. 1995, "Cross-cultural validation of existing quality of life scales", *Patient Education and Counselling*, vol. 26, pp. 313-318.
- Clark, L. T., Ferdinand K.C., Flack, J. M., Gavin J.R., Hall W.D., Kumanyika S.K., Reed J.W., Saunders E, Valantine H.A., Watson K., Wenger NK, & Wright JT 2001, "Coronary heart disease in African Americans", *Heart Disease*, vol. 3, no. 2, pp. 97-108.
- Coffey, A., Holbrook, B., & Atkinson, P. 1996, "Qualitative data analysis: technologies and representations", *Sociological Research Online*, vol. 1, no. 1. Available from <<http://www.socresonline.org.uk/1/14.html>> [29 March 2004].
- Conroy, S. P. & Mayberry, J. F. 2001, "Patient information booklets for Asian patients with ulcerative colitis", *Public Health*, vol. 115, no. 6, pp. 418-420.
- Cook, D. G., Shaper, A. G., & Macfarlane, P. W. 1989, "Using the WHO (Rose) angina questionnaire in cardiovascular epidemiology", *International Journal of Epidemiology*, vol. 18, no. 3, pp. 607-613.
- Cornwell, J. 1984, *Hard earned lives: accounts of health and illness from East London*, Tavistock, London.
- Cosin, J., Asin, E., Marrugat, J., Elosua, R., Aros, F., de los Reyes, M., Castro-Beiras, A., Cabades, A., Diago, J. L., Lopez-Bescos, L., & Vila, J. 1999, "Prevalence of angina pectoris in Spain. PANES study group", *European Journal of Epidemiology*, vol. 15, no. 4, pp. 323-330.
- Currer, C. & Stacey, M. (eds) 1986, *Concepts of health, illness and disease: a comparative perspective*, Berg, Leamington Spa.
- Curtis, S., Gesler, W., Smith, G., & Washburn, S. 2000, "Approaches to sampling and case selection in qualitative research: examples in the geography of health", *Social Science and Medicine*, vol. 50, pp. 1001-1004.
- Curtis, S. & Lawson, K. 2000, "Gender, ethnicity and self-reported health: the case of African-Caribbean populations in London", *Social Science and Medicine*, vol. 50, pp. 365-385.
- Dalton, M. & Hampton, K. 1994, *Scotland's ethnic minority community 1991: A Census summary*, Glasgow Caledonian University, Scottish Ethnic Minorities Research Unit Fact Sheet Number 1. Glasgow Caledonian University, Glasgow.

- Deutscher, I. 1973, "Asking questions cross-culturally; some problems of linguistic comparability," in *Comparative Research Methods*, D. Warwick & S. Osherson, eds., Prentice Hall, New Jersey, pp. 163-188.
- Deyo, R. A. 1984, "Pitfalls in measuring the health status of Mexican Americans: comparative validity of the English and Spanish Sickness Impact Profile", *American Journal of Public Health*, vol. 74, no. 6, pp. 569-573.
- Ebden, P., Carey, O. J., Bhatt, A., & Harrison, B. 1998, "The bilingual consultation", *The Lancet*, vol. 13, no. 1, p. 347.
- Edwards, R. R. & Fillingim, R. B. 1999, "Ethnic differences in thermal pain responses", *Psychosomatic Medicine*, vol. 61, pp. 346-354.
- Engel, G. L. 1980, "The clinical application of the biopsychosocial model", *American Journal of Psychiatry*, vol. 137, pp. 535-544.
- Entwistle, V., Renfrew, M. J., Yearly, S., Forrester, J., & Lamont, T. 1998, "Lay perspectives: advantages for health research", *British Medical Journal*, vol. 316, pp. 463-466.
- Erens, B., Primatesta, P., Prior, G., 2001, *Health Survey for England: The Health of Minority Ethnic Groups*, The Stationery Office, London.
- Erikssen, J., Forfang, K., & Storstein, O. 1977, "Angina pectoris in presumably healthy middle-aged men", *European Journal of Cardiology*, vol. 6, no. 4, pp. 285-298.
- Eyton, J. & Neuwirth, G. 1984, "Cross-cultural validity: ethnocentrism in health studies with special reference to the Vietnamese", *Social Science and Medicine*, vol. 18, no. 5, pp. 447-453.
- Fabrega, H. 1975, "The need for an ethnomedical science", *Science*, vol. 189, pp. 969-975.
- Fabrega, H. & Tyma, S. 1976, "Language and cultural influences in the description of pain", *British Journal of Medical Psychology*, vol. 49, pp. 349-371.
- Facione, N. C., Giancarlo, C., & Chan, L. 2000, "Perceived risk and help-seeking behaviour for breast cancer. A Chinese-American perspective", *Cancer Nursing*, vol. 23, no. 4, pp. 258-267.
- Farooqi, A., Nagra, D., Edgar, T., & Khunti, K. 2000, "Attitudes to lifestyle risk factors for coronary heart disease amongst South Asians in Leicester: a focus group study", *Family Practice*, vol. 17, no. 4, pp. 293-297.
- Feder, G., Crook, A. M., Magee, P., Banerjee, S., Timmins, A. D., & Hemingway, H. 2002, "Ethnic differences in invasive management of coronary disease: prospective cohort study of patients undergoing angiography", *British Medical Journal*, vol. 324, no. 511, p. 516.



- Feinleib, M., Lambert, P. M., Zeiner-Henriksen, T., Rogot, E., Hunt, B. M., & Ingster-Moore, L. 1982, "The British-Norwegian Migrant Study- Analysis of parameters of mortality differentials associated with angina", *Biometrics*, vol. 38 (Supplement), pp. 55-71.
- Fenton, S. & Sadiq-Sangster, A. 1996, "Culture, relativism and the expression of mental distress: South Asian women in Britain", *Sociology of Health and Illness*, vol. 18, no. 1, pp. 66-85.
- Fischbacher, C. M., Bhopal, R., Unwin, N., White, M., & Alberti, K. G. M. M. 2001, "The performance of the Rose Angina Questionnaire in a South Asian population: a comparative study in Newcastle, UK", *International Journal of Epidemiology*, vol. 30, pp. 1009-1016.
- Flannery, R. B., Sos, J., & McGovern, P. 1981, "Ethnicity as a factor in the expression of pain", *Psychosomatics*, vol. 22, no. 1, pp. 39-50.
- Fong, C. L. & Watt, I. 1994, "Chinese health behaviour: breaking barriers to better understanding", *Health Trends*, vol. 26, no. 1, pp. 14-15.
- Gandek, B. & Ware, J. E. 1998, "Methods for validating and norming translations of health status questionnaires: the IQOLA project approach", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 953-959.
- General Medical Council 2000. *Confidentiality: Protecting and providing information*, General Medical Council, London,
- Gill, P. S., Kai, J., Bhopal, R. S., & Wild, S. in press, "Health Care Needs Assessment: Black and Minority Ethnic Groups," in *Health Care Needs Assessment. The epidemiologically based needs assessment reviews*, J. Raftery, ed., Radcliffe Medical Press Ltd., Abingdon. Also available from <<http://hcna.radcliffe-oxford.com/bemgframe.htm>> [29 March 2004].
- Good, B. J. 1977, "The heart of what's the matter. The semantics of illness in Iran", *Culture, Medicine and Psychiatry*, vol. 1, no. 1, pp. 25-58.
- Goodare, H. & Lockwood, S. 1999, "Involving patients in clinical research: improves the quality of research", *British Medical Journal*, vol. 319, pp. 724-725.
- Graham-Garcia, J., Raines, T. L., Andrews, J. O., & Mensah, G. A. 2001, "Race, ethnicity and geography: disparities in heart disease in women of color", *Journal of Transcultural Nursing*, vol. 12, no. 1, pp. 56-67.
- Greene, A. F., Schocken, D. D., & Spielberger, C. D. 1991, "Self-report of chest pain symptoms and coronary artery disease in patients undergoing angiography", *Pain*, vol. 47, no. 3, pp. 319-324.
- Greenhalgh, T., Helman, C., & Chowdhury, A. M. 1998, "Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study", *British Medical Journal*, vol. 316, pp. 978-983.

Greenwald, H. P. 1991, "Interethnic differences in pain perception", *Pain*, vol. 44, pp. 157-163.

Guillemin, F., Bombardier, C., & Beaton, D. 1993, "Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines", *Journal of Clinical Epidemiology*, vol. 46, no. 12, pp. 1417-1432.

Gupta, M., Doobay, A. V., Singh, N., Anand, S. S., Raja, F., Mawji, F., Kho, J., Karavetian, A., Yi, Q., & Yusuf, S. 2002, "Risk factors, hospital management and outcomes after acute myocardial infarction in South Asian Canadians and matched control subjects", *Canadian Medical Association Journal*, vol. 166, no. 6, pp. 717-722.

Gupta, M., Tabas, J. A., & Kohn, M. A. 2002, "Presenting complaint among patients with myocardial infarction who present to an urban, public hospital emergency department", *Annals of Emergency Medicine*, vol. 40, no. 2, pp. 180-186.

Gupta, S. P. & Malhotra, K. C. 1975, "Urban-rural trends in the epidemiology of coronary heart disease", *Journal of the Association of Indian Physicians*, vol. 22, pp. 885-892.

Hagman, M., Jonsson, D., & Wilhemsen, L. 1977, "Prevalence of angina pectoris and myocardial infarction in a general population sample of Swedish men", *Acta Medica Scandinavica*, vol. 201, pp. 571-577.

Harding, S. & Maxwell, R. 1997, "Differences in mortality of migrants," in *Health Inequalities*, F. W. M. Drever, ed., Office for National Statistics, London, pp. 108-121.

Harland, J. O., Unwin, N., Bhopal, R. S., White, M., Watson, B., Laker, M., & Alberti, K. G. 1997, "Low levels of cardiovascular risk factors and coronary heart disease in a UK Chinese population", *Journal of Epidemiology and Community Health*, vol. 51, no. 6, pp. 636-642.

Harris, R. B. & Weissfeld, L. A. 1991, "Gender differences in the reliability of reporting symptoms of angina pectoris", *Journal of Clinical Epidemiology*, vol. 44, no. 10, pp. 1071-1078.

Hawthorne, K. 1994, "Accessibility and use of health care services in the British Asian community", *Family Practice*, vol. 11, no. 4, pp. 453-459.

Haywood, L. J., Ell, K., Sobel, E., deGuzman, M., & Blumfield, D. 1993, "Rose Questionnaire Responses among black, latino and white subjects in two socioeconomic strata", *Ethnicity and Disease*, vol. 3, no. 3, pp. 303-314.

Health Education Authority 1999, *Health and lifestyles of the Chinese population in England*, Health Education Authority, London.

Health Education Authority 2000, *Black and minority ethnic groups in England: the second health and lifestyles survey*, Health Education Authority, London.

- Heine, S., Lehman, D., Peng, K., & Greenholtz, J. 2002, "What's wrong with cross-cultural comparisons of subjective Likert scales?: The reference-group effect", *Journal of Personality and Social Psychology*, vol. 82, no. 6, pp. 903-918.
- Helman C.G. 2000, *Culture, Health and Illness*, 4th edn, Butterworth-Heinemann, Oxford.
- Hendricson, W. D., Russell, J., Prihoda, T. J., Jacobson, J. M., Rogan, A., & Bishop, G. D. 1989, "An approach to developing a valid Spanish language translation of a health status questionnaire", *Medical Care*, vol. 27, no. 10, pp. 959-967.
- Herdman, M., Fox-Rushby, J., & Badia, X. 1997, "'Equivalence' and the translation and adaptation of health-related quality of life questionnaires", *Quality of Life Research*, vol. 6, pp. 237-247.
- Herdman, M., Fox-Rushby, J., & Badia, X. 1998, "A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach", *Quality of Life Research*, vol. 7, pp. 323-335.
- Hughes, A. O., Fenton, S., & Hine, C. E. 1995, "Strategies for sampling black and ethnic minority populations", *Journal of Public Health Medicine*, vol. 17, no. 2, pp. 187-192.
- Hunt, S. & Bhopal, R. 2003, "Self reports in research with non- English speakers", *British Medical Journal*, vol. 327, pp. 353-354.
- Hunt, S. 1998, "Cross-cultural issues in the use of quality of life measures in randomized controlled trials," in *Quality of Life Assessment in Clinical Trials*, M. Staguet, R. Hays, & P. Fayers, eds., Oxford University Press, Oxford, pp. 51-67.
- Hunt, S. M. 1993, "Cross-cultural comparability of measures and other issues related to multicountry studies", *British Journal of Medical Economics*, vol. 6C, pp. 27-54.
- Hunt, S. M. 1994, "Developing a measure of quality of life for adults with growth hormone deficiency", *Drug Information Journal* , vol. 28, pp. 3-11.
- Hunt, S. M., McEwan, J., & McKenna, S. 1986, *Measuring health status* Croom Helm, Beckenham.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. 1998, "Review of community based research: assessing partnership approaches to improve public health", *Annual Review of Public Health*, vol. 19, pp. 173-202.
- Jensen, G. Epidemiology of chest pain and angina pectoris (with special reference to treatment needs). *Acta Medica Scandinavia Supplementum* 682. 1984.
- Jones, K. 2003, *Mission Drift in Qualitative Research, or Moving toward a systematic review of qualitative studies, moving back to a more systematic narrative review*, *The Qualitative Report*. [Online] Centre for Evidence in Ethnicity, Health

and Diversity working paper, available at:

<<http://users.wbs.warwick.ac.uk/chess/ceehd/ceehd.htm>> [29 March 2004]

Jonsdottir, L. S., Sigfusson, N., Sigvaldson, H., & Thorgeirsson, G. 1998, "Incidence and prevalence of recognised and unrecognised myocardial infarction in women. The Reykjavik Study.", *European Heart Journal*, vol. 19, no. 7, pp. 1011-1018.

Kai, J. & Hedges, C. 1999, "Minority ethnic community participation in needs assessment and service development in primary care: perceptions of Pakistani and Bangladeshi people about psychological distress", *Health Expectations*, vol. 2, pp. 7-20.

Kannel, W. B. & Feinleib, M. 1972, "Natural history of angina pectoris in the Framingham study: Prognoses and survival", *American Journal of Cardiology*, vol. 29, pp. 154-163.

Keen, H. & Jarrett, R. J. 1979, "The WHO multinational study of vascular disease in diabetes: 2. Macrovascular Disease Prevalence", *Diabetes Care*, vol. 2, no. 2, pp. 187-195.

Keller, S. D., Ware, J. E., Gandek, B., Aaronson, N. K., Alonso, J., Apolone, G., Bjorner, J. B., Brazier, J., Bullinger, M., Fukuhara, S., Kaasa, S., Leplege, A., Sanson-Fisher, R. W., Sullivan, M., & Wood-Dauphine, S. 1998, "Testing the equivalence of translations of widely used response choice labels: results from the IQOLA Project", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 933-944.

Kelman, S. 1975, "The social nature of the definition problem in health", *International Journal of Health Services*, vol. 5, pp. 625-641.

Kernicki, J. G. 1997, "A multicultural perspective of cardiovascular disease", *Journal of Cardiovascular Nursing*, vol. 11, no. 4, pp. 31-40.

Kleinman A 1980, "Major conceptual and research issues for cultural (anthropological) psychiatry", *Culture, Medicine & Psychiatry*, vol. 41, no. 1, pp. 3-13.

Kleinman, A. 1987, "Anthropology and psychiatry. The role of culture in cross-cultural research on illness", *British Journal of Psychiatry*, vol. 151, pp. 447-454.

Kleinman, A., Eisenberg, L., & Good, B. 1978, "Culture, illness and care: Clinical lessons from anthropologic and cross-cultural research", *Annals of Internal Medicine*, vol. 88, pp. 251-258.

Kleinman, A. M. 1977, "Depression, somatization and the 'new cross-cultural psychiatry'", *Social Science and Medicine*, vol. 11, pp. 3-10.

Klingler, D., Green-Weir, R., Nerenz, D., Havstad, S., Rosman, H. S., Cetner, L., Shah, S., Wimbush, F., & Borzak, S. 2002, "Perceptions of chest pain differ by race", *American Heart Journal*, vol. 144, no. 51, p. 59.



- Koo, L. C. 1987, "Concepts of disease causation, treatment and prevention among Hong Kong Chinese: diversity and eclecticism", *Social Science and Medicine*, vol. 25, no. 4, pp. 405-417.
- Koopman, C., Eisenthal, S., & Stoeckle, J. D. 1984, "Ethnicity in the reported pain, emotional distress and requests of medical outpatients", *Social Science in Medicine*, vol. 18, no. 6, pp. 487-490.
- Krause, I.-B. 1989, "Sinking heart: a Punjabi communication of distress", *Social Science and Medicine*, vol. 29, no. 4, pp. 563-575.
- Krogh, V., Trevisan, M., Panico, S., Farinaro, E., Mancini, M., Menotti, A., & Ricci, G. 1991, "Prevalence and correlates of angina pectoris in the Italian nine communities study", *Epidemiology*, vol. 2, no. 1, pp. 26-32.
- Kutty, V. R., Balakrishnan, K. G., Jayasree, A. K., & Thomas, J. 1993, "Prevalence of coronary heart disease in the rural population of Thiruvananthapuram district, Kerala, India", *International Journal of Cardiology*, vol. 39, pp. 59-70.
- LaCroix, A., Haynes, S. G., Savage, D. D., & Havlik, R. J. 1989, "Rose Questionnaire Angina among United States Black, White, and Mexican-American women and men", *American Journal of Epidemiology*, vol. 129, no. 4, pp. 669-686.
- LaCroix, A. Z., Guralnik, J. M., Curb, J. D., Wallace, R. B., Ostfeld, A. M., & Hennekens, C. H. 1990, "Chest pain and coronary heart disease mortality among older men and women in three communities", *Circulation*, vol. 81, no. 2, pp. 437-446.
- Lambert, H. & McKevitt, C. 2002, "Anthropology in health research: from qualitative methods to multidisciplinary", *British Medical Journal*, vol. 325, pp. 210-213.
- Lambert, H. & Sevak, L. 1996, "Is cultural difference a useful concept? Perceptions of health and the sources of ill health among Londoners of South Asian origin," in *Researching cultural differences in health*, D. Kelleher & S. Hillier, eds., Routledge, London, pp. 124-159.
- Langford, H. G., Oberman, A., Borhani, N. O., Entwistle, G., & Tung, B. 1984, "Black-white comparison of indices of coronary heart disease and myocardial infarction in the stepped-care cohort of the Hypertension Detection and Follow-Up program", *American Heart Journal*, vol. 108, pp. 797-801.
- Larose, R. & Fawcett, P. (rev). 1997, "Théories contemporaines de la traduction", *Translator*, vol. 3, no. 2, pp. 242-246.
- Last, J. M. (ed.), 1995, *A dictionary of epidemiology*, 3rd edn, Oxford University Press, Oxford.

- Lau, K. C. J., Stewart, S. M., & Fielding, R. 2001, "Preliminary evaluation of 'interpreter' role plays in teaching communication skills to medical undergraduates", *Medical Education*, vol. 35, pp. 217-221.
- Laws, M. B., Heckscher, R., Mayo, S. J., Li, W., & Wilson, I. B. 2004, "A new method for evaluating the quality of medical interpretation", *Medical Care*, vol. 42, no. 1, pp. 71-80.
- Leplege, A., Ecosse, E., Verdier, A., & Perneger, T. V. 1998, "The French SF-36 Health Survey: Translation, cultural adaptation and preliminary psychometric evaluation", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 1013-1023.
- Lewin, R. J. P., Furze, G., Robinson, J., Griffith, K., Wiseman, S., Pye, M., & Boyle, R. 2002, "A randomised controlled trial of a self-management plan for patients with newly diagnosed angina", *British Journal of General Practice*, vol. 52, pp. 194-201.
- Liao, X.-H. & McIlwaine, G. 1995, "The health status and health needs of Chinese population in Glasgow", *Scottish Medical Journal*, vol. 40, pp. 77-80.
- Linn, L. S., Ware, J. E., & Greenfield, S. 1980, "Factors associated with relief from chest pain following emergency care", *Medical Care*, vol. 18, no. 6, pp. 624-634.
- Lip, G. Y. H., Cader, M. Z., Lee, F., Munir, S. M., & Beevers, D. G. 1996, "Ethnic differences in pre-admission levels of physical activity in patients admitted with myocardial infarction", *International Journal of Cardiology*, vol. 56, pp. 169-175.
- Lipton, J. A. & Marbach, J. J. 1984, "Ethnicity and the pain experience", *Social Science in Medicine*, vol. 19, no. 12, pp. 1279-1298.
- Lundman, T., Liljefors, I., Cederlof, R., & Friberg, L. 1971, "The validity of the questionnaire diagnosis", *Archives of Environmental Health*, vol. 22, pp. 597-599.
- Macaskill, S. & Petrie, M. 2000, *I didn't come here for fun- listening to the views of children and young people who are refugees or asylum-seekers in Scotland*, Save the Children, Edinburgh.
- Macauley, A. C., Commanda, L. E., Freeman, W. L., Gibson, N., McCabe, M. L., Robbins, C. M., & Twohig, P. L. 1999, "Participatory research maximises community and lay involvement", *British Medical Journal*, vol. 319, pp. 774-778.
- Madhavan S, Cohen H., & Alderman MH 1995, "Angina pectoris by Rose questionnaire does not predict cardiovascular disease in treated hypertensive patients", *Journal of Hypertension*, vol. 13, no. 11, pp. 1307-1312.
- Madhok, R., Hameed, A., & Bhopal, R. 1998, "Satisfaction with health services among the Pakistani population in Middlesbrough, England", *Journal of Public Health Medicine*, vol. 20, no. 3, pp. 295-301.
- Mays, N. & Pope, C. 2000, "Qualitative research in health care. Assessing quality in qualitative research", *British Medical Journal*, vol. 320, pp. 50-52.

- McKeigue, P. M. 1989, "Coronary heart disease in South Asians overseas: a review.", *Journal of Clinical Epidemiology*, vol. 42, pp. 597-609.
- Medalie, J., Snyder, M., Groen, J. J., Neufeld, H. N., Goldbourt, U., & Riss, E. 1973, "Angina Pectoris among 10,000 men", *The American Journal of Medicine*, vol. 55, pp. 583-594.
- Meraji, S., Abuja, P. M., Hayn, M., Kostner, G. M., Morris, R., Oraii, S., Tatzber, F., Wonisch, W., Zechner, R., & Gey, K. F. 2000, "Relationship between classic risk factors, plasma antioxidants and indicators of oxidant stress in angina pectoris (AP) in Tehran", *Atherosclerosis*, vol. 150, no. 2, pp. 403-412.
- Miller, G. J., Beckles, G. L. A., Maude, G. H., Carson, D. C., Alexis, S. D., Price, S. G. L., & Byam, N. T. A. 1989, "Ethnicity and other characteristics predictive of coronary heart disease in a developing community: principal results of the St James Survey, Trinidad", *International Journal of Epidemiology*, vol. 18, no. 4, pp. 808-817.
- Mitchell, B. D., Hazuda, H. P., Haffner, S. M., Patterson, J. K., & Stern, M. P. 1991, "High prevalence of angina pectoris in Mexican-American men. A population with reduced risk of myocardial infarction", *Annals of Epidemiology*, vol. 1, no. 5, pp. 415-426.
- Montero, D. 1977, "Research among racial and cultural minorities: an overview", *Journal of Social Issues*, vol. 33, pp. 1-10.
- Moore, R. 1990, "Ethnographic assessment of pain coping perceptions", *Psychosomatic Medicine*, vol. 52, pp. 171-181.
- Morrisey, B. 2003, *Health education for ethnic minorities in Lothian: current provision and evaluation*, 4th year Special Study Module, University of Edinburgh, Edinburgh.
- Moussa, M. E., Gadallah, M., & Mortagy, A. K. 1994, "The evaluation of an Arabic version of Rose Questionnaire", *The Journal of the Egyptian Public Health Association*, vol. 69, pp. 31-46.
- Myers, V. 1977, "Survey methods for minority populations", *Journal of Social Issues*, vol. 33, no. 4, pp. 12-19.
- Nanchahal, K., Mangtani, P., Alston, M., & dos Santos Silva, I. 2001, "Development and validation of a computerised South Asian Names and Group Recognition Algorithm (SANGRA) for use in British health-related studies", *Journal of Public Health Medicine*, vol. 23, no. 4, pp. 278-285.
- Nazroo, J. Y. 1998, "Genetic, cultural or socio-economic vulnerability? Explaining ethnic inequalities in health", *Sociology of Health and Illness*, vol. 20, no. 5, pp. 710-730.

- Nevid, J. S. & Maria, N. L. S. 1999, "Multicultural issues in qualitative research", *Psychology and Marketing*, vol. 16, no. 4, pp. 305-325.
- Ng, B., Dimsdale, J. E., Rollnik, J. D., & Shapiro, H. 1996, "The effect of ethnicity on prescriptions for patient-controlled analgesia for post-operative pain", *Pain*, vol. 66, pp. 9-12.
- O'Loughlin, J. 1999, "Understanding the role of ethnicity in chronic disease: a challenge for the new millennium", *Canadian Medical Association Journal*, vol. 161, pp. 152-153.
- Oakley, A. 1999, "People's ways of knowing: gender and methodology," in *Critical issues in social research*, S. Hood, B. Mayall, & S. Oliver, eds., Open University Press, UK, pp. 155-170.
- Owen-Smith, V., Hannaford, P. C., & Elliot, A. M. 2003, "Increased mortality among women with Rose angina who have not presented with ischaemic heart disease", *British Journal of General Practice*, vol. 53, no. 495, pp. 784-789.
- Pasick, R. J., Stewart, S. L., Bird, J. A., & D'Onofrio, C. N. 2001, "Quality of data in multiethnic health surveys", *Public Health Reports*, vol. 116, no. Supplement 1, pp. 223-243.
- Patel, D. J., Winterbotham, M., Sutherland, S. E., Britt, R. G., Keil, G. C., & Sutton, G. C. 1997, "Comparison of methods to assess coronary heart disease prevalence in South Asians", *The National Medical Journal of India*, vol. 10, no. 5, pp. 210-213.
- Patel, K.C.R. & Bhopal, R.S., eds. 2004, *The epidemic of coronary heart disease in South Asian populations: causes and consequences*, The South Asian Health Foundation, Birmingham.
- Perkoff, G. T. & Strand, M. 1973, "Race and presenting complaints in myocardial infarction", *American Heart Journal*, vol. 85, no. 5, pp. 716-717.
- Perneger, T. V., Leplege, A., & Etter, J. F. 1999, "Cross-cultural adaptation of a psychometric instrument: two methods compared", *Journal of Clinical Epidemiology*, vol. 52, no. 11, pp. 1037-1046.
- Pfeffer, N. 1998, "Theories of race, ethnicity and culture", *British Medical Journal*, vol. 317, pp. 1381-1384.
- Pfeffer, N. & Moynihan, C. 1996, "Ethnicity and health beliefs with respect to cancer: a critical review of methodology", *British Journal of Cancer Supplement*, vol. 29, p. S66-S72.
- Pope, C., Ziebland, S., & Mays, N. 2000, "Qualitative research in health care. Analysing qualitative data", *British Medical Journal*, vol. 320, pp. 114-117.
- Pugh, J. F. 1991, "The semantics of pain in Indian culture and medicine", *Culture, Medicine and Psychiatry*, vol. 15, pp. 19-43.



- Racy, J. 1980, "Somatization in Saudi women: a therapeutic challenge", *British Journal of Psychiatry*, vol. 137, pp. 212-216.
- Raczynski, J. M., Taylor, H., Cutter, G., Hardin, M., & Oberman, A. 2001, "Rose Questionnaire responses among black and white inpatients admitted for coronary heart disease: findings from the Birmingham-BHS project", *Ethnicity and Disease*, vol. 3, no. 3, pp. 290-302.
- Rankin, J. & Bhopal, R. 2001, "Understanding of heart disease and diabetes in a South Asian community: cross-sectional study testing the 'snowball' sample method", *Public Health*, vol. 115, no. 4, pp. 253-260.
- Rapola, J. M., Virtamo, J., Haukka, J. K., Heinonen, O. P., Albanes, D., Taylor, P. R., & Huttunen, J. K. 1996, "Effect of vitamin E and Beta Carotene on the incidence of angina pectoris: a randomised, double-blind, controlled trial", *JAMA*, vol. 275, no. 9, pp. 693-698.
- Reunanen, A., Aromaa, A., Pyorala, K., Punsar, S., Maatela, J., & Knekt, P. The Social Insurance Institution's Coronary Heart Disease study. Baseline data and five-year mortality experience. Acta Medica Scandinavia Supplementum 673. 1983.
- Richards, H. M., Reid, M. E., & Watt, G. C. 2002, "Socioeconomic variations in responses to chest pain: qualitative study", *British Medical Journal*, vol. 324, p. 1308.
- Rose, G. 1968, "Variability of angina. Some implications for epidemiology", *British Journal of Preventive and Social Medicine*, vol. 22, pp. 12-15.
- Rose, G., McCartney, P., & Reid, D. D. 1977, "Self-administration of a questionnaire on chest pain and intermittent claudication", *British Journal of Preventive and Social Medicine*, vol. 31, pp. 42-48.
- Rose, G. A. 1962, "The diagnosis of ischaemic heart pain and intermittent claudication in field surveys", *Bulletin of the World Health Organisation*, vol. 27, pp. 645-658.
- Rose, G. A. 1965, "Chest pain questionnaire", *Millbank Memorial Fund Quarterly*, vol. 43, pp. 32-39.
- Rose, G. A., Blackburn, H., Gillum, R. F., & Prineas, R. J. 1982, *Cardiovascular survey methods*, 2nd edn, World Health Organisation, Geneva.
- Rossouw, J. E., Weich, H. F. H., Steyn, K., Kotze, J. P., & Kotze, T. J. v. W. 1984, "The prevalence of ischaemic heart disease in three rural South African communities", *Journal of Chronic Diseases*, vol. 37, no. 2, pp. 97-106.
- Salber, E. J. & Beza, A. G. 1980, "The health interview survey and minority health", *Medical Care*, vol. 18, no. 3, pp. 319-326.

Sanson-Fisher, R. W. & Perkins, J. J. 1998, "Adaptation and validation of the SF-36 health survey for use in Australia", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 961-967.

Satia, J. A., Patterson, R. E., Taylor, V. M., Cheney, C. L., Shiu-Thornton, S., Chitnarong, K., & Kristal, A. R. 2000, "Use of qualitative methods to study diet, acculturation, and health in Chinese-American women", *Journal of the American Dietetic Association*, vol. 100, no. 8, pp. 934-940.

Schulman KA., Berlin JA, Harless W., Kerner JF, Dube R, Burke JE, Williams S, & Escarce JJ 1999, "The effect of race and sex on physicians' recommendations for cardiac catheterization", *New England Journal of Medicine*, vol. 340, no. 8, pp. 618-626.

Schwandt, T. A. 1994, "Constructivist, interpretivist approaches to human inquiry," in *Handbook of qualitative research*, N. K. Denzin & Y. S. Lincoln, eds., Sage, London, pp. 118-137.

Senior, P. A. & Bhopal, R. S. 1994, "Ethnicity as a variable in epidemiological research", *British Medical Journal*, vol. 309, pp. 327-330.

Sensky, T. 1996, "Eliciting lay beliefs across cultures: principles and methodology", *British Journal of Cancer Supplement*, vol. 29, p. S63-S65.

Smaje, C. & Le Grand, J. 1997, "Ethnicity, equity and the use of health services in the British NHS", *Social Science and Medicine*, vol. 45, no. 3, pp. 485-496.

Small, R., Yelland, J., Lumley, J., & Rice, P. L. 1999a, "Cross-cultural research: trying to do it better. 1. Issues in study design", *Australian and New Zealand Journal of Public Health*, vol. 23, no. 4, pp. 385-395.

Small, R., Yelland, J., Lumley, J., Rice, P. L., Cotronei, V., & Warren, R. 1999b, "Cross-cultural research: trying to do it better. 2. Enhancing data quality", *Australian and New Zealand Journal of Public Health*, vol. 23, no. 4, pp. 390-395.

Smith, K. W., McGraw, S. A., Crawford, S. L., & McKinlay, J. B. 1993, "Do blacks and whites differ in reporting Rose Questionnaire Angina? Results of the Boston Health Care Project", *Ethnicity and Disease*, vol. 3, no. 3, pp. 278-289.

Sollors, W. 1996, "Foreword: Theories of American ethnicity," in *Theories of Ethnicity: A classical reader*, W. Sollors, ed., Macmillan Press Ltd, p. x-xliv.

Sorlie, P. D., Cooper, L., Schreiner, P. J., Rosamond, W., & Szklo, M. 1996, "Repeatability and validity of the Rose Questionnaire for angina pectoris in the Atherosclerosis Risk in Communities Study", *Journal of Clinical Epidemiology*, vol. 49, pp. 719-725.

Streltzer, J. & Wade, T. C. 1981, "The influence of cultural group on the undertreatment of postoperative pain", *Psychosomatic Medicine*, vol. 43, no. 5, pp. 397-403.

Sullivan, M. & Karlsson, J. 1998, "The Swedish SF-36 Health Survey III. Evaluation of criterion-based validity: results from normative population", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 1105-1113.

Sun SS, Huang JL, Ho YJ, & Kao CH 2001, "The higher likelihood of developing cardiomegaly during follow-up in patients with syndrome X and abnormal thallium-201 myocardial perfusion SPECT", *International Journal of Cardiac Imaging*, vol. 17, no. 4, pp. 271-278.

Temple, B. 1997, "Watch your tongue: issues in translation and cross-cultural research", *Sociology*, vol. 31, pp. 607-618.

The British Council 1999. *Views of Britain: Population of Great Britain*. [Online], Available from < [http://elt.britcoun.org.pl/s\\_fco.htm](http://elt.britcoun.org.pl/s_fco.htm) > [29 March 2004]

The WHOQOL group 1998, "The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties", *Social Science & Medicine*, vol. 46, no. 12, pp. 1569-1585.

Thompson, D., ed. 1995, *The Concise Oxford Dictionary*, 9th edn, Clarendon Press, Oxford.

Tibblin L. 1981, "Oesophageal dysfunction and angina pectoris in a Swedish population selected at random ", *Acta Medica Scandinavica Supplementum*, vol. 644, pp. 71-74.

Tiengo, A., Briani, G., Jori, E., Fedele, D., Grigoletto, F., Trevisan, R., & ESDNN Study Group 1996, "Prevalence of micro- and macro-albuminuria in Italian Type II (non-insulin dependent) diabetic patients", *Diabetes, nutrition & metabolism*, vol. 9, pp. 59-66.

Todd, K. H., Deaton, C., D'Adamo, A. P., & Goe, L. 2000, "Ethnicity and analgesic practice", *Annals of Emergency Medicine*, vol. 35, no. 1, pp. 10-16.

Twinn, S. 1997, "An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research", *Journal of Advanced Nursing*, vol. 26, pp. 418-423.

Twinn S & Cheng F 2000, "Increasing uptake rates of cervical cancer screening amongst Hong Kong Chinese women: the role of the practitioner", *Journal of Advanced Nursing*, vol. 32, no. 2, pp. 335-342.

Uusitalo, A., Keyrilainen, O., & Johnsson, G. 1981, "A dose-response study on metoprolol in angina pectoris", *Annals of Clinical Research*, vol. 13, no. Suppl 30, pp. 54-57.

Van den Akker, O. B. A., Eves, F. F., Service, S., & Lennon, B. 1995, "Menstrual cycle symptom reporting in three British ethnic groups", *Social Science and Medicine*, vol. 40, pp. 1417-1423.

Verthein, U. & Kohler, T. 1997, "The correlation between everyday stress and angina pectoris: a longitudinal study", *Journal of Psychosomatic Research*, vol. 43, no. 3, pp. 241-245.

Wagner, A., Simon, C., Evans, A., Ferrieres, J., Montaye, M., Ducimetiere, P., & Arvelier, D. 2002, "Physical activity and coronary event incidence in Northern Ireland and France", *Circulation*, vol. 105, pp. 2247-2252.

Wagner, A. K., Gandek, B., Aaronson, N. K., Acquadro, C., Alonso, J., Apolone, G., Bullinger, M., Bjorner, J., Fukuhara, S., Kaasa, S., Lepke, A., Sullivan, M., Wood-Dauphinee, S., & Ware, J. E. 1998, "Cross-cultural comparisons of the content of SF-36 translations across 10 countries: results from the IQOLA project", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 925-932.

Ware, J. E. & Gandek, B. 1998a, "Methods for testing data quality, scaling assumptions, and reliability: The IQOLA project approach", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 945-952.

Ware, J. E. & Gandek, B. 1998b, "Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) project", *Journal of Clinical Epidemiology*, vol. 51, no. 11, pp. 903-912.

Ware, J. E., Keller, S. D., Gandek, B., Brazier, J. E., & Sullivan, M. 1995, "Evaluating translations of health status questionnaires", *International Journal of Technology Assessment in Health Care*, vol. 11, no. 3, pp. 525-551.

Warnecke, R. B. 1997, "Improving question wording in surveys of culturally diverse populations", *Annals of Epidemiology*, vol. 7, no. 5, pp. 334-342.

Warnecke, R. B., Ferrans, C. E., Johnson, T. P., Chapa-Resendez, G., O'Rourke, G., Chavez, N., Dudas, S., Smith, E. D., Martinez Schallmoser, L., Hand, R. P., & Lad, T. 1996, "Measuring quality of life in culturally diverse populations", *Journal of the National Cancer Institute Monographs*, vol. 20, pp. 29-38.

Warner, C. D. 1995, "Somatic awareness and coronary artery disease in women with chest pain", *Heart and Lung*, vol. 24, no. 6, pp. 436-443.

Webster, R. 1997, "The experiences and health care needs of Asian coronary patients and their partners. Methodological issues and preliminary findings", *Nursing in Critical Care*, vol. 2, pp. 215-223.

White, G. M. 1982, "The role of cultural explanations in 'somatization' and 'psychologization'", *Social Science and Medicine*, vol. 16, pp. 1519-1530.

White, M., Bush, J., Kai, J., Bhopal, R., & Rankin, J. 2002, *A study to explore the feasibility and acceptability of smoking cessation interventions among Bangladeshi and Pakistani men and women*, Cancer Research UK & University of Newcastle, Newcastle.

- Wiebe, E. R., Sent, L., Fong, S., & Chan, J. 2002, "Barriers to use of oral contraceptives in ethnic Chinese women presenting for abortion", *Contraception*, vol. 65, no. 2, pp. 159-163.
- Wilbush, J. 1985, "Surveys of climacteric semiology in non-Western populations: a critique", *Maturitas*, vol. 7, pp. 289-296.
- Wilcosky, T., Harris, R., & Weissfeld, L. 1987, "The prevalence and correlates of Rose Questionnaire angina among women and men in the Lipid Research Clinics Program Prevalence Study population", *American Journal of Epidemiology*, vol. 125, pp. 400-409.
- Wilcox, S., Ainsworth, B. E., LaMonte, M. J., & DuBose, K. D. 2002, "Worry regarding major diseases among older African-American, Native-American, and Caucasian women", *Women & Health*, vol. 36, no. 3, pp. 83-99.
- Wild, S. & McKeigue, P. 1997, "Cross sectional analysis of mortality by country of birth in England and Wales, 1970-1992", *British Medical Journal*, vol. 314, pp. 705-710.
- Wilkinson, K. 2001, "Pakistani women's perceptions and experiences of incontinence", *Nursing Standard*, vol. 16, no. 5, pp. 33-39.
- Williams, R., Bhopal, R., & Hunt, K. 1993, "The health of a Punjabi ethnic minority in Glasgow: a comparison with the general population", *Journal of Epidemiology and Community Health*, vol. 47, pp. 96-102.
- Williams, R., Eley, S., Hunt, K., & Bhatt, S. 1997, "Has psychological distress among UK South Asians been under-estimated? A comparison of three measures in the west of Scotland population.", *Ethnicity and Health*, vol. 2, pp. 21-29.
- Williams, R. & Hunt, K. 1997, "Psychological distress among British South Asians: the contribution of stressful situations and subcultural differences in the West of Scotland Twenty-07 Study", *Psychological Medicine*, vol. 27, pp. 1173-1181.
- Williams, R. B. 1999, "A 69-year-old man with anger and angina", *Journal of the American Medical Association*, vol. 282, no. 8, pp. 763-770.
- Yazar, J. & Littlewood, R. 2001, "Against over-interpretation: the understanding of pain amongst Turkish and Kurdish speakers in London", *International Journal of Social Psychiatry*, vol. 47, no. 2, pp. 20-33.
- Zborowski, M. 1952, "Cultural components in responses to pain", *Journal of Social Issues*, vol. 8, pp. 16-30.
- Zola, I. K. 1966, "Culture and symptoms: an analysis of patients' presenting complaints", *American Sociological Review*, vol. 31, pp. 615-630.

**Appendix 1      Publication screening pro-forma for Rose Angina  
Questionnaire review**



## Publication screening pro-forma

Q1 Q2	Article: first author, year of publication and journal		
Q3	Source of reference	1 SSCI/ SCI-EXP search 2 Medline 1966-01 search 3	
Q4	The paper focuses on a discussion of methodological issues relating to the use of the Rose angina questionnaire in non-English language or non-European ethnic settings		1 yes -> include go to Q18 0 no 9 uncertain
Q5	Rose angina questionnaire used	0 no -> exclude paper go to Q18 1 paper states "Rose", "London School of Hygiene" or "WHO" questionnaire used 2 CHD or angina interview/ questionnaire mentioned, citing Rose reference 9 no info -> exclude paper go to Q18	
Q6	Language in which the Rose angina questionnaire was administered	0 states language was English for all participants -> exclude, go to Q18 1 stated, and not English for all participants 9 not stated	
Q7	Geographical location of study population stated (1=yes (specify) 9= not stated)		
Q8	Ethnicity/ culture of study population stated (1=yes (specify) 9 = unclear or no information given)		
Q9	Main (non-English) language of study population stated (1=yes (specify) 9 = unclear or no information given)		
Q10	Location of study institution stated (1=yes (specify city, country) 9 = not stated)		
Q11	Study institution (or site of study if stated) in an area where non-English language could be assumed for any population survey		1 yes 0 no
Q12	The paper includes a description of the process of translation or cross-cultural adaptation		1 yes -> photocopy description 0 no
Q13	comment on adaptation details (if any) (0= no comments)		
Q14	Study name for linked group of papers (ie one study with several papers in this review) (0=not part of linked group)		
Q15	Methods paper 1 for this article (first author, year) (0=none; 8= not required)		
Q16	Methods paper 2 for this article (first author, year) (0=none; 8= not required)		
Q17	Methods paper 3 for this article (first author, year) (0=none; 8 = not required)		
Q18	Photocopy of article in file		1 yes 0 no, article reviewed Walton library 2 no, article reviewed Edinburgh library
Q19	Final category 0 - exclude 1 - cross-cultural methodology paper 2 - single (non-English/ Euro) cultural group study 3 - comparison of Rose in two cultural groups	4 - duplicate - ie another paper included in review describes study methods 5 - 8 - paper not found 9 - uncertain	
Notes no interviewed:			

## Publication data abstraction pro-forma

complete if paper in final categories 1-3 for Q19

Q20	Non-English language used (best guess depending on location of institution and study population if details not otherwise provided)		
Q21	Self completion or face to face	1 self completion 2 face to face interview 9 no information	
Q22	In relation to the questionnaire/ interview described, paper cites Rose 1962 (Bull WHO)	1 yes 0 no	
Q23	In relation to the questionnaire/ interview described, paper cites Rose 1965 (Millbank MFQ)	1 yes 0 no	
Q24	In relation to the questionnaire/ interview described, paper cites Rose 1968 (Br J Pr So Med)	1 yes 0 no	
Q25	In relation to the questionnaire/ interview described, paper cites Rose 1977 (Br J Pr So Med)	1 yes 0 no	
Q26	In relation to the questionnaire/ interview described, paper cites Rose 1982 (WHO technical)	1 yes 0 no	
Q27	Details of questionnaire administration (enter 1 if details given and specify (and photocopy methods section), 9 if no details given)		
Q28	Description of translation process (enter 1 if details given and specify (and photocopy methods section), 9 if no details given)		
Q29	Description of adaptation process (enter 1 if details given and specify (and photocopy methods section), 9 if no details given)		
Q30	Comparative data reported that could be used to verify diagnosis of angina (ECG, clinical diagnosis, prognostic information - code 1 and describe if given, code 9 if none)		
Q31	Possibly relevant articles to obtain from paper reference list (code 0 if none)		
Q32	Reviewer 1=Colin Fischbacher 2 = Lisa Hanna 3=		
Q33	Date of review		

<b>Current Pro-forma status (enter at top of front page)</b>	4	request to Lisa Hanna to get
0 reference not coded	5	waiting for methods paper
1 for review in Newcastle library	6	waiting for related papers
2 not in Newcastle library	7	
3 interlibrary loan requested	9	paper reviewed (complete)



**Appendix 2      Translations of the Rose Angina  
Questionnaire used in the Newcastle Heart  
Project (Punjabi, Chinese)**

ਕੀ ਤੁਹਾਨੂੰ ਕਦੇ ਤੁਹਾਡੀ ਛਾਤੀ ਵਿੱਚ ਕੋਈ ਦਰਦ ਜਾਂ ਤਕਲੀਫ਼ ਹੋਈ ਹੈ ?

a) Have you ever had any pain or discomfort in your chest ?

ਹਾਂ Yes 1  
(go to Q3b) (Q3b ਤੇ ਜਾਓ)

ਨਹੀਂ No 2  
(go to Q4) (Q4 ਤੇ ਜਾਓ)

 12

b) Do you get this pain or discomfort when you walk up hill or hurry ?

ਕੀ ਤੁਹਾਨੂੰ ਇਹ ਦਰਦ ਜਾਂ ਤਕਲੀਫ਼ ਉਦੋਂ ਹੁੰਦੀ ਹੈ ਜਦੋਂ ਤੁਸੀਂ ਚੜ੍ਹਾਈ ਚੜ੍ਹਦੇ  
ਹੋ ਜਾਂ ਜਲਦੀ ਵਿੱਚ ਹੁੰਦੇ ਹੋ ?

Yes ਹਾਂ 1

No ਨਹੀਂ 2

 13

c) Do you get it when you walk at an ordinary pace on the level ?

ਕੀ ਤੁਹਾਨੂੰ ਇਹ ਦਰਦ ਜਾਂ ਤਕਲੀਫ਼ ਉਦੋਂ ਹੁੰਦੀ ਹੈ ਜਦੋਂ ਤੁਸੀਂ ਆਮ ਪੱਧਰੀ ਥਾਂ ਤੇ  
ਟਾਂਹਲਦੇ ਹੋ ?

Yes ਹਾਂ 1

No ਨਹੀਂ 2

 14

ਜਦੋਂ ਤੁਹਾਨੂੰ ਤੁਹਾਡੀ ਛਾਤੀ ਵਿੱਚ ਦਰਦ ਜਾਂ ਤਕਲੀਫ਼ ਹੁੰਦੀ ਹੈ, ਤਾਂ ਤੁਸੀਂ ਕੀ ਕਰਦੇ ਹੋ ?

d) When you get any pains or discomfort in your chest, what do you do ?

ਰੁੱਕ ਜਾਂਦੇ ਹੋ Stop 1

ਹੌਲੀ ਹੋ ਜਾਂਦੇ ਹੋ Slow Down 2

ਉਸੇ ਤਰ੍ਹਾਂ ਜਾਰੀ ਰੱਖਦੇ ਹੋ Continue at the same pace 3

 15

e) Does it go away when you stand still ?

ਕੀ ਇਹ ਦਰਦ ਬੰਦ ਹੋ ਜਾਂਦਾ ਹੈ ਜਦੋਂ ਤੁਸੀਂ ਸਥਿਰ ਖੜ੍ਹੇ ਹੋ ਜਾਂਦੇ ਹੋ ?

Yes ਹਾਂ 1

No ਨਹੀਂ 2

 16

ਇਹ ਕਿੰਨੀ ਜਲਦੀ ਥੰਦ ਹੋ ਜਾਂਦਾ ਹੈ ?

3f) How soon does it go away ?

10 ਮਿੰਟ ਦੇ ਵਿੱਚ ਜਾਂ ਤੋਂ ਘੱਟ

In 10 minutes or less

1

10 ਮਿੰਟਾਂ ਤੋਂ ਜ਼ਿਆਦਾ ਦੇ ਵਿੱਚ

In more than 10 minutes

2

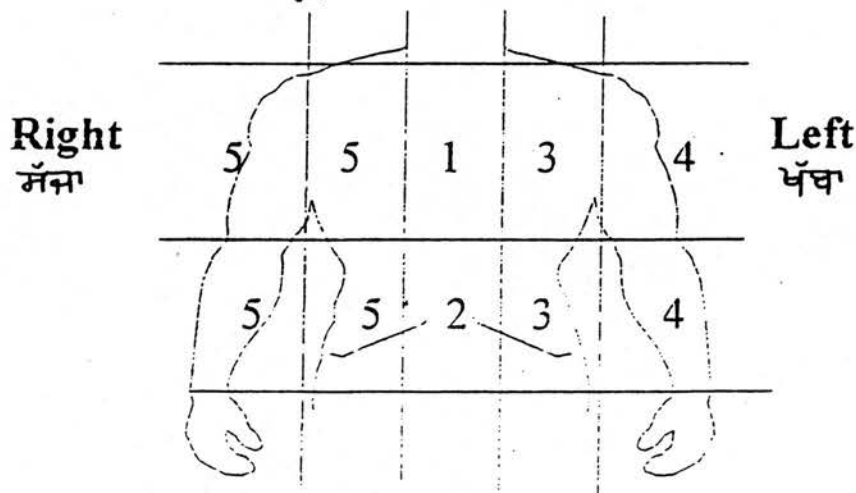
17

ਤੁਹਾਨੂੰ ਇਹ ਦਰਦ ਜਾਂ ਅਕਸੀਫ ਕਿਥੇ ਹੁੰਦੀ ਹੈ ?

3g) Where do you get this pain or discomfort ?

( mark a X (or X's) on the diagram and DO NOT code )

(ਰੇਖਾ ਚਿੱਤਰ ਤੇ ਕਾਂਟਾ(X) ਜਾਂ ਕਾਂਟੇ(X's) ਦਾ ਨਿਸ਼ਾਨ ਲਗਾਉ ਅਤੇ ਕੋਡ ਨਾ ਕਰੋ)




18

ਕੀ ਤੁਹਾਨੂੰ ਕਦੇ ਤੁਹਾਡੀ ਛਾਤੀ ਦੇ ਮੁਹੱਲੇ(ਅਥਲੇ) ਹਿੱਸੇ ਵਿੱਚ ਸਖਤ ਦਰਦ ਹੋਇਆ ਹੈ ਜਿਹੜਾ ਕਿ ਅੱਧਾ ਘੰਟਾ ਜਾਂ ਇਸ ਤੋਂ ਜ਼ਿਆਦਾ ਦੇਰ ਰਿਹਾ ਹੋਵੇ ?

4a) Have you ever had a severe pain across the front of your chest

lasting half an hour or more ?

ਹਾਂ

Yes

( go to Q4b) (Q4b ਤੇ ਜਾਉ)

1

ਨਹੀਂ

No

( go to Q5) (Q5 ਤੇ ਜਾਉ)

2

19

ਕੀ ਤੁਸੀਂ ਡਾਕਟਰ ਨਾਲ ਇਸ ਬਾਰੇ ਗਲ ਕੀਤੀ ਸੀ ?

4b) Did you talk to a doctor about it ?

ਹਾਂ

Yes

( go to Q4c) (Q4c ਤੇ ਜਾਉ)

1

ਨਹੀਂ

No

( go to Q5) (Q5 ਤੇ ਜਾਉ)

2

20

3

## 問卷 (WHO QUESTIONNAIRE)

1. (a). 你以往曾經有過胸部痛或胸部不適嗎  
 1. 有      2. 沒有      9. 不知道      ☐

- (b). 如果沒有, 你以前有沒有感覺到有些重, 壓在胸口部位?  
 1. 有      2. 沒有      9. 不知道      ☐  
 假如答案是“沒有”, 請轉答問題 3.

- (c). 當你行斜坡或步行急促時, 便得此症狀?  
 1. 是      2. 不是  
 3. 未行過急步或上斜坡      ☐  
 假如答案是“不是”, 請轉答問題 2.

- (d). 當你在平地步行時, 是否也得此症狀?  
 1. 是      2. 不是      ☐

- (e). 當你步行時得此症狀, 你會怎樣做?  
 1. 停步或減慢腳步      2. 繼續步行  
 [假如你服食過 NITROGLYCERINE (含在舌底的一種止痛丸) 而又繼續步行的話, 請填答案“1. 停步或減慢腳步”]  
 假如答案是“2. 繼續步行”, 請轉答問題 2.

- (f). 如果你停止步行, 你的胸部痛覺得怎樣?  
 1. 減輕痛楚      2. 仍然痛楚      ☐

- (g). 要多久才減輕痛楚呢?

1. 要 10 分鐘或少過  
 2. 要多過 10 分鐘      ☐

假如答案是“2. 多過 10 分鐘”, 請轉答問題 2.

(h.) 你請指出痛楚是位於那處呢？

1. 是 2. 不是 (填上 1. 或 2. 在以下每一項的小格內)

胸骨 (在上部或中部位置)

☐

胸骨 (在下部位置)

☐

左前胸部

☐

左手臂

☐

其他部位

☐

(i.) 你是否感覺到痛楚也在其他部位？

1. 是 2. 不是

☐

如果是，請詳加說明

---

---

(j.) 你有沒有因此痛楚而看醫生？

1. 有 2. 沒有

☐

假如“有”，醫生說這症狀是甚麼

請寫你的意見

---

---

(k.) 你以前有沒有做過心臟動脈手術？

(冠狀動脈移植手術)

1. 有 2. 沒有

☐

如果“有”，說明在那一年做過手術？

(如果未有做過手術，填上 99 在格內)

19

2. (a.) 你以往是否有過嚴重的胸部痛楚是持續約半小時或多過？

1. 有 2. 沒有

☐

如果“有”，說明最近發生的日期

(b.) 你以前有沒有因為此痛楚而看醫生？

1. 有                      2. 沒有

└

假如“有”，醫生說是甚麼？

---

---

## **Appendix 3      Telephone screening interview form**



<b>Project worker:</b>	<b>Date/time:</b>
<b>Participant ID:</b>	<b>Participant's language:</b>
<b>Participant's age:</b>	<b>Interview? Yes                  No</b>

### Telephone screening interview

1. *Introduction and explanation-* e.g. "Hello, can I speak to [participants' name?] please? Hello there, my name is [your name] and I'm a project worker from the University of Edinburgh. I'm ringing concerning the research project on pain and ill-health that you kindly agreed to talk to us about. Do you have a few free minutes to talk to me at the minute?"

*If yes:*

Many thanks for agreeing to let me ring you. I wonder if you could help me by answering just a few questions about yourself. All this information will be totally confidential and anonymous, but please remember that you don't have to answer any question you'd rather not and your care from your doctor will not be affected in any way. OK?

2. Which languages can you speak?

3. What is your mother tongue?

4. What is the language you prefer to speak?

5. Do you speak this language at home?

**6. If you were asked to complete a survey questionnaire or interview, and offered a choice of languages, which language would you choose?**

7. What is your country of birth?

8. What is your age/ age range?

9. How long have you lived in Edinburgh?

10. Where did you live before that?

11. *Introduction to health questions:* Now I'm going to ask you a few questions about your experience of pain and ill-health. Could you please just give me a yes or no answer at this stage?

12. Have you ever had any indigestion?

13. Have you ever had any pain when taking exercise?

**14. Have you ever had any pain or discomfort in your chest?**

15. Have you seen your GP in the past year?

16. How many times per year would you go to your GP?

17. Thank you so much for answering those questions for me today.

Either:

a) I'd like to talk to you a bit more about what you've told me today- would you be prepared to have a longer chat with me? I could come to your home at a time convenient to you. It should take up about 45 minutes or an hour of your time, and we would really appreciate it.

*If yes, arrange a time and place for interview. Remember to ask for the participants' address.*

OR

b) That's all I need to ask you at the minute, so can I just say that your help has been very much appreciated.

**Appendix 4      Communications with Lothian Research  
Ethics Committee following submission of an  
application for ethical approval for the study**

OUR REF: LREC/2000/3/19

YOUR REF:

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Lisa Hanna  
Public Health Sciences  
University of Edinburgh  
Medical School, Teviot Place  
Edinburgh EH8 9AG

20 September 2000

Dear Ms Hanna,

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

Thank you for submitting the above protocol for ethical approval. The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee has discussed this protocol at its recent meeting but has deferred making a decision and continued consideration for the following reasons:-

- Reassurance is required that project workers involved in the study will be culturally and linguistically competent.
- There was some concern regarding patient confidentiality and the release of patient details by General Practitioners. It was suggested that the initial letter should be sent out on GP surgery headed notepaper and signed by the patients GP rather than the researcher. The letter should state that patients will be telephoned after two weeks, not one week, and that if they do not want this to happen they should contact the surgery during these two weeks. When telephone contact is made the researcher should explain that they are phoning from, or on behalf, of the GP surgery. The letter should be written in English and the relevant native language i.e. Punjabi
- Please clarify who will extract the information from patients notes – will surgeries be expected to do this or will somebody from the research team extract the relevant information?

The next meeting of the Sub-Committee will be held on 13 October 2000. It would be appreciated if the required amendments could be available prior to that date.

Yours sincerely

**ANNETTE HARRIS**

Administrator

Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee





LISA HANNA

PUBLIC HEALTH SCIENCES  
Department of Community Health Sciences

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Fax 0131 650 6909

Telephone 0131 650 1000

or direct dial 0131 650 3230

9<sup>th</sup> October 2000

Ref: LREC/ 2000/ 3/ 19

Lisa.Hanna@ed.ac.uk

Dear Ms Harris,

**Re: The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

I would be grateful if you could submit the following letter and amendments to the Healthy Studies/ Public Health Medicine Research Ethics Sub-Committee. I thank the committee for their comments, which I have carefully considered. I enclose 17 copies of this letter and attached amendments for the committee members, and also enclose a full copy of the application form for your records.

- *Reassurance is required that project workers involved in the study will be culturally and linguistically competent.*

Professor Raj Bhopal, one of the academic supervisors for this study, has worked extensively in the area of ethnicity and health and was one of the leaders of the Newcastle Heart Project, a multi-ethnic study employing many project interviewers and workers. He is currently involved in qualitative research on a CRC funded study of tobacco use in Pakistani and Bangladeshi people in Newcastle, which is breaking new ground in this area, particularly in training interviewers. I will draw on Professor Bhopal's considerable expertise in this area, and that of a number of his colleagues with whom I am in contact, to inform the recruitment, selection and training process for the project workers. Fully bilingual co-workers will be ethnically, linguistically and gender matched with the participant groups, and will be recruited via local

and gender matched with the participant groups, and will be recruited via local community networks and organisations. They will be required at interview to take an approved language test, a process that has been shown to be crucial in appointing staff for qualitative research projects such as this, to ensure adequate linguistic and translating skills. We envisage using, with permission, a job description similar to that used in a recent study in Newcastle (see attached person specification for an approximate list of the type of qualifications and skills we will be asking for). Successful candidates will then be involved in an intensive 2-day training session, to give them a thorough practical, theoretical and ideological grounding in the rationale and aims of the project and develop uniform interviewing skills. Such a training session will include role-plays and discussion of possible scenarios. Throughout the project, the applicant and her supervisors and advisors will work closely and reflexively with the project workers to deal with any issues that may arise, provide informative support and receive feedback.

- *There was some concern regarding patient confidentiality and the release of patient details by general practitioners. It was suggested that the initial letter should be sent out on GP surgery headed notepaper and signed by the patients GP rather than the researcher.*

The sample letter to study participants we submitted to the committee indicated that it would be written on jointly headed notepaper, to show collaboration between the General Practice and the University. All other documents sent to study participants would also have both General Practice and University letterheads. We are sure the committee will not wish us to give the wrong impression that this work was being done solely on the behalf of the General Practice (both in the letter and when the telephone contact is made). We believe that the participants should be aware that they are taking part in an independent research project. It is important to avoid "medicalising" the interview experience in order to achieve opinions and expressions free of a medical mindset. We are concerned that if the study is too strongly associated with the general practice, the participants may feel less able to give frank ("private" as opposed to "public") accounts of their experiences and reactions. We have, however, amended the letter to include joint signatures of the applicant and the participant's GP (see attached amended letter).

- *The letter should state that patients will be telephoned after two weeks, not one week, and that if they do not want this to happen they should contact the surgery during these two weeks.*

As recommended, we have amended the time span during which the participant can refuse consent to be telephoned, to two weeks (see attached amended Question 20, Page 12; and amended letter). However for the reasons outlined above in response to the previous concern, we think it is better research practice for the refusal forms (enclosed in stamped addressed envelopes with the introductory letter) to be returned to the applicant at the University, not to the General Practice.

- *When telephone contact is made the researcher should explain that they are phoning from, or on behalf, of the GP surgery.*

As stated above in response to the previous two concerns, we think that participants may feel less free to refuse if they perceive the study as being performed by their GP, as they may feel it might affect their care. The sense of respect and deference to the medical profession may be particularly high, both due to the cultural background of some of the respondents, and as a function of their age. We think it is better research practice for the interviewer to state that they are ringing on behalf of a project being done by the University in association with the General Practice.

- *The letter should be written in English and the relevant native language i.e. Punjabi*

We are happy to provide each participant with a copy of the letter both in Punjabi or Cantonese as appropriate and in English; this may facilitate discussion of the project with other family members more fluent in English.

- *Please clarify who will extract the information from patients' notes- will surgeries be expected to do this or will somebody from the research team extract the relevant information?*

No medical information will be required from the patients' case notes, as stated in the original application (Question 14b, Page 7; Question 38, Page 18). As stated in the application (Question 17a, Page 9), we are only interested in obtaining access to GP registers and selecting an age and gender stratified sample of participants from each

ethnic group via a combination of name search (a process shown to be efficacious in selecting participants of South Asian and Chinese origin) and asking practice staff about the ethnic or linguistic origin of the potential participants. We will examine the practices' name registers, then ask a practice staff member to confirm, if possible, the ethnic and linguistic origin of the participant. As stated in the application (Question 17a, Page 9; Question 17d, Page 10), the participant's GP will then be asked to confirm that the participant is able to take part in the study. At all stages the GP will be giving consent.

---

**19. Is written consent to be obtained?**

Yes

*If yes, please attach a copy of the consent form to be used.*

Refusal and consent forms attached (one refusing consent to be telephoned, one giving consent to be interviewed).

*If no written consent is to be obtained, please justify.*

N/A

---

**20. How long will the subject have to decide whether to take part in the study?**

*If less than 24 hours please justify.*

The participant will have two weeks to return the refusal letter before being telephoned. If the patient agrees to be telephoned, and meet the selection criteria, they will be asked if they would be prepared to take part in a longer interview. If they agree, an interview time will be decided upon, probably within the next week or fortnight following telephone contact. Upon arrival, the participant will be asked to sign a consent form. So from initial informative letter to interview, the participant may have up to four weeks to decide whether or not to be interviewed, and three opportunities to decline involvement during that time.

---

**21. Please attach a copy of the written information sheet or letter to be given to the subject.**

*(See Guidelines page 3 and Appendix A.)*

Participant information sheet and letter attached

*If no Information Sheet is to be given, please justify.*

N/A

---

**22. Have any special arrangements been made for subjects for whom English is not a first language?**

Yes

*If yes, give details.*

Bilingual project co-workers will be recruited and trained to carry out the telephone calls and interviews in the participant's language (Punjabi or Cantonese). The participant information sheet and consent forms will be translated into Punjabi and Cantonese for use with participants from these linguistic groups.

*If no, please justify.*

N/A

---

**23. Will any of the subjects or controls be from one of the following vulnerable groups?**

Children under 16

People with learning difficulties

Unconscious or severely ill

Other vulnerable groups e.g. mental illness, dementia

**Letter of invitation to research participants**

**Letterheads of both the University of Edinburgh and of the General practice(s)**

Address

Date

Dear (name of patient)

**Re: Your understanding of health problems**

Understanding how people from different communities understand and speak about certain health problems (such as indigestion, discomfort in the chest, or pain when taking exercise) is really important in order to improve health and health care for all ethnic groups. Your doctor's surgery is involved in a study carried out by the University of Edinburgh. We are interested in your understanding of certain health problems and why you go to the doctor.

We are writing to ask if someone could phone you at home to ask you one or two questions about the language you prefer to speak and about your experience of certain health problems, if any, and to ask whether you would be willing to help with the study. Helping would mean talking to someone who speaks your language in your own home, if convenient, for about an hour.

We have enclosed an information sheet giving you more details about the study to help you decide. Whatever you decide about helping with the study, your care from your practice will not be affected. If you do not want to receive a phone call or to take any further part at this stage, we would be grateful if you would complete and return the enclosed refusal form.

If we **do not** hear from you in the next two weeks, we will contact you by telephone in about two weeks' time.

Your help in this study would be very much appreciated.  
Thank you.

Yours sincerely,

GP's name

Lisa Hanna  
University of Edinburgh Medical Faculty  
Doctoral Researcher

Enc.

The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire  
*Person Specification for the post of project workers for a qualitative study of chest pain in Punjabi and Cantonese men and women*

Criteria	Essential	Desirable	Means of Assessment
Education, qualifications and training	<ul style="list-style-type: none"> <li>Completed secondary school education</li> </ul>	<ul style="list-style-type: none"> <li>Qualification in English</li> <li>Qualification in Punjabi or Cantonese</li> <li>Qualification in interpretation or translation</li> <li>Qualification in community or qualitative research</li> </ul>	<ul style="list-style-type: none"> <li>CV</li> </ul>
Experience		<ul style="list-style-type: none"> <li>Knowledge of Punjabi-speaking or Cantonese-speaking communities in Edinburgh</li> <li>Talking to people in a professional capacity</li> <li>Professional interpretation or translation</li> <li>Research interviewing</li> <li>Health care or health promotion work</li> <li>Keyboard, computing or word processing skills</li> </ul>	<ul style="list-style-type: none"> <li>CV</li> </ul>
Skills	<ul style="list-style-type: none"> <li>Excellent verbal communication</li> <li>Fluency in English</li> <li>Fluency in Punjabi or Cantonese</li> <li>Ability to translate from Punjabi or Cantonese into English and vice versa</li> <li>Ability to translate from interview tapes into English</li> </ul>	<ul style="list-style-type: none"> <li>Good written communication</li> </ul>	<ul style="list-style-type: none"> <li>Interview and language test</li> </ul>
Personal qualities	<ul style="list-style-type: none"> <li>An ability to work closely with people from a range of different cultural backgrounds</li> <li>Ability to work both independently and as a member of a team</li> <li>Respect for privacy and confidentiality</li> <li>Respect for alternative lifestyles</li> <li>Able to work flexible hours</li> <li>Well organised</li> </ul>	<ul style="list-style-type: none"> <li>Self motivation</li> <li>Ability to work well with regular supervision</li> </ul>	<ul style="list-style-type: none"> <li>CV and interview</li> </ul>

With thanks to Dr. Judith Bush (University of Newcastle) and colleagues (Dr Martin White, Dr Joe Kai)



OUR REF: LREC/2000/3/19

YOUR REF:

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Lisa Hanna  
Public Health Sciences  
University of Edinburgh  
Medical School, Teviot Place  
Edinburgh EH8 9AG

19 October 2000

Dear Ms Hanna,

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

Thank you for submitting your amendments to the above protocol for ethical approval. The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee has discussed this protocol at its recent meeting but has deferred making a decision for the following reasons:-

**AS MINUTED:**

'The sub-committee noted the receipt of the required information and agreed that this satisfied all but one of its concerns.

The outstanding issue concerned patient confidentiality and the release of patient details by General Practitioners, the sub-committee noting recent guidance from the GMC that general practitioners should not release information on patients without patient consent.

It was agreed that the suggestion provided by Dr Hanna was not acceptable and it was agreed that she would be asked to make the amendments as stated previously.'

If you do not feel that the amendments previously suggested by the sub-committee are acceptable, the sub-committee would like to invite you to its next meeting to discuss this issue. The next meeting of the Sub-Committee will be held at 4 pm on Friday 3 November 2000 in meeting room 1 at Deaconess House, 148 Pleasance, Edinburgh.

I would be grateful if you would confirm prior to 3 November whether you will be attending the meeting. A copy of the GMC statement is enclosed for your information.

Yours sincerely

**ANNETTE HARRIS**

Administrator

Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee



PUBLIC HEALTH SCIENCES  
Department of Community Health Sciences

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Fax 0131 650 6909  
Telephone 0131 650 1000

or direct dial 0131 650 3230

Lisa.Hanna@ed.ac.uk

27<sup>th</sup> October 2000

Ref: LREC/ 2000/ 3/ 19

Dear Ms Harris

**Re: The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

Further to your communication from the sub-committee concerning my application for ethical approval as follows (one correction- I am a PhD student and am therefore Ms as opposed to Dr Hanna):

- *"The sub-committee noted the receipt of the required information and agreed that this satisfied all but one of its concerns. The outstanding issue concerned patient confidentiality and the release of patient details by General Practitioners, the sub-committee noting recent guidance from the GMC that general practitioners should not release information on patients without patient consent. It was agreed that the suggestion provided by Ms Hanna was not acceptable and it was agreed that she would be asked to make the amendments as stated previously."*

In discussion with my supervisor, Professor Raj Bhopal, we have considered the sub-committee's suggestions and feel we are more clear about the objections raised. If it is the case that the initial letter is sent by the GP asking the participant whether the practice can release contact details to the researchers for subsequent contact, then we acknowledge that this is a crucial step ensuring consent and patient confidentiality. We attach an amended letter, which will be sent from the GP to the participant. The participant will then return the refusal form to the General Practice if they do not wish their telephone number or contact details to be released to the researchers. If they do not return the refusal form in the designated two weeks, the GP will then release their contact details to the researcher, who will subsequently contact the participant by telephone. At this stage however we feel it is vital to inform them that the research project is being done independently. As stated in my last letter, we think it is better research practice for the interviewer to state that they are ringing on behalf of a project being done by the University in association with the General Practice.

We feel it is important to stress that this study depends on co-operation between the General Practice and the researchers, who have the necessary expertise available in ethnicity and health research to identify a sample from a named register. We would therefore need to examine the practice's name registers, but would require no access to further identifiable information such as address, postcode or telephone number until after the GP has informed the patient of the study and been granted consent to disclose their contact details.

Please find attached the amended appropriate sections of the application form (Question 14 a) i; Question 17 (a) (b) (d); Question 19; Question 20; Question 31) and the amended letter to the patient from their GP, participant information sheet and refusal form. I enclose 17 copies of this letter and attached documents for inspection by the sub-committee, and one full copy of the application form for your records.

We hope that these amendments are satisfactory to the sub-committee. However, I (Lisa Hanna) would be happy to attend the next sub-committee meeting on Friday 3<sup>rd</sup> November to discuss any issues that might remain and clarify any further points.

Yours sincerely,

Lisa Hanna.

**Letter of invitation to research participants**

**General practice headed notepaper**

Address

Date

Dear (name of patient)

**Re: Your understanding of health problems**

Understanding how people from different communities understand and speak about certain health problems (such as indigestion, discomfort in the chest, or pain when taking exercise) is really important in order to improve health and health care for all ethnic groups. Our general practice is involved in a study about ethnicity and health carried out by Lisa Hanna from the University of Edinburgh, under the guidance of Professor Raj Bhopal and Dr Sonja Hunt. They are interested in your understanding of certain health problems and why you go to the doctor.

We are writing to ask whether you give consent for us to release your name, telephone number and address to the researchers at the University of Edinburgh. If you agree, someone would phone you at home to ask you a few questions about the language you prefer to speak and about your experience of certain health problems, if any, and to ask whether you would be willing to help with the study. Helping would mean talking to someone who speaks your language either in your own home or another convenient place, for about an hour.

We have enclosed an information sheet giving you more details about the study to help you decide. Whatever you decide about helping with the study, your care from us at your practice will not be affected. If you do not want us to reveal your contact details we would be grateful if you would complete and return the enclosed refusal form.

If we **do not** hear from you in the next two weeks, we will allow the researchers to have access to your name, address and telephone number and to contact you by telephone in about two weeks' time. We stress that the researchers will treat this information as strictly confidential. We will not be giving the researchers any medical information about you.

Your help in this study would be very much appreciated.  
Thank you.

Yours sincerely,

GP's name

NOTE: THE FOLLOWING INFORMATION SHEET WILL BE TRANSLATED INTO PUNJABI OR CANTONESE AS APPROPRIATE. WHILST IN THIS VERSION, ALL ALTERNATIVES ARE INCLUDED (EG PUNJABI/ CANTONESE/ ENGLISH, NAMES OF CO-WORKERS ETC), THE FINAL TRANSLATED VERSIONS WILL INCLUDE ONLY THAT INFORMATION THAT IS PERTINENT TO THE SPECIFIC LINGUISTIC GROUP.

.....

### **Participant Information Sheet**

University of Edinburgh/ General Practice headed paper

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

Thank you for reading this.

## **YOUR UNDERSTANDING OF HEALTH PROBLEMS**

### *What is the aim of the study?*

This study aims to explore how people speaking different languages express their understanding of some common health problems, how they interpret certain questions about these health problems, and why they seek medical attention for these problems. It will involve speaking to a number of Punjabi speaking people, Cantonese speaking people and English speaking people to see if there are differences between them. The study will last for a further two years.

### *Who is organising and funding the research?*

The study is being done by Lisa Hanna, a doctoral researcher at Edinburgh University. Lisa is assisted by a Punjabi speaking project co-worker [name] and a Cantonese speaking co-worker [name]. The study is funded by a Medical Faculty Research Scholarship and by [additional funding details]. Your GP is not receiving payment for including you in this study. The study is supported by Professor Raj Bhopal and Dr Sonja Hunt at the University of Edinburgh.

### *Why have I been chosen?*

We want to in talk to people from different language groups about their experience and understanding of symptoms of ill-health. Your name has been selected from the list of South Asian/ Chinese/ British patients on the surgery's



register who are believed to speak Punjabi/ Cantonese/ English, and who are over 45 years of age. Altogether 100 people from each language group have been selected to be contacted initially by phone. From these about 20 people in each language group will be asked to take part in a longer face-to-face discussion.

*What will happen to me if I take part?*

[Appropriate co-worker] would like to telephone you at home on one occasion to ask you which language you prefer to speak and a few simple questions about your experience of certain symptoms of ill-health. This telephone call should take up no more than five minutes of your time. Then you might be asked if [appropriate name] could visit you in your own home, if convenient, for a longer interview. This visit should last about an hour. We need to tape-record the conversation so that we have an accurate account of what has been discussed. If you agree, together we will arrange a convenient time for you to be interviewed. After this interview, you may be asked whether you would be prepared to talk to Lisa or [name of co-worker] again at a later date in order to check that you agree with our findings.

*Do I have to take part?*

It is up to you to decide whether or not to take part. If you do not want to take part, you can return the refusal form to your GP and they will not give us your telephone number and you will not be contacted at all. If you are telephoned and you decide to take part in the interviews, you will be given a consent form to sign, but you can stop at any time. You also need not answer any question you'd rather not. Whatever you decide, your current or future care from your doctor will not be affected in any way.

*What happens to this information? Is it confidential?*

You will be asked to sign a written consent form indicating your willingness to participate in this study. Whilst your GP will be notified of your participation in the study, any information you share will be treated as strictly confidential. No information will be passed back to the practice or your doctor unless you request this to happen. The only person/ people who will know what you yourself have said is/are Lisa/ and [appropriate bilingual project co-worker].

You will not be identified by name either on the tapes or in any notes. Your name and any identifying details will be kept securely in a locked filing cabinet and will be destroyed at the end of the study in approximately two years time.

The results of this study will form a doctoral thesis by Lisa Hanna for the University of Edinburgh. This written work is likely to be completed in about two years time. A summary of the study will be available for you to read if you desire. A summary of the research will also be sent to the participating general practice and to the funding bodies at the end of the study. This work may be published so that people in the NHS and elsewhere can read it and improve future research on the health of different ethnic groups. In this and



all other written reports your name is not mentioned and no-one will know from the reports what you have said.

*What are the benefits of taking part?*

Understanding how people from different communities understand and speak about health problems is really important in improving the health and health care of all ethnic groups. The information we get from this study may help us treat future Punjabi/ Cantonese/ English-speaking patients better.

*Who has reviewed this study?*

Lothian Research Ethics Public Health Medicine Sub-Committee have reviewed this study.

*Contact for further information*

You are welcome to contact Lisa, [Punjabi-speaking co-worker(s)] or [Cantonese speaking co-worker(s)] at the address or phone number given in the attached letter if you want further information at any time.

You are also welcome to contact Antonia Ineson, the Independent Adviser for the study, if you have concerns at any stage.

You may contact her at:

Health Promotion,  
Lothian Health,  
Deaconess House,  
148 Pleasance,  
Edinburgh  
EH8 9RS  
Telephone: (0131) 536 9425

Thank you for taking the time to read this information sheet. Please consider participating in this study. Your help would be much appreciated.

This information sheet is yours to keep.

Should you decide to participate in this study you will also be given a copy of your signed consent form to keep.

Date:

Version number:

**NOTE TO COMMITTEE: THIS REFUSAL FORM WILL BE TRANSLATED INTO PUNJABI AND CANTONESE FOR PEOPLE FROM THESE LINGUISTIC GROUPS.**

.....  
**General Practice headed paper**

**REFUSAL FORM (TO BE RETURNED TO GENERAL PRACTICE IN ATTACHED STAMPED ADDRESSED ENVELOPE)**

**Name:**

**Address:**

**Date:**

**Re: Your understanding of health problems**

**I do not permit my GP to give my name, address and telephone number to the ethnicity and health researchers at the University of Edinburgh.**

**Signature:**

**11. Brief outline of project including outcome measures (Maximum. 250 words)**

The meaning, perception and experience of health events are best investigated by a qualitative approach. This study will conduct semi-structured interviews, yielding qualitative data of people's perceptions, expressions and assessments. Specific, quantitative outcome measures do therefore not apply to this study.

This project will investigate the perception and expression of chest pain in three different ethnic/linguistic groups (Punjabi speakers, Cantonese speakers, white British English speakers). Existing translated versions of the Rose Angina Questionnaire will then be assessed by these monolingual lay populations.

A sample of approximately 100 people from each of the three linguistic groups, 300 in total, will be selected (see question 17 for selection criteria) from one or more general practice registers. All selected participants will be telephoned by a bilingual project co-worker and asked some preliminary questions. On the basis of their responses to the brief (less than 5 minutes) telephone interview, 20 participants from each of the three linguistic groups will be selected (see question 17 for selection criteria) for interview.

At interview, the participants will be asked about their experience and perception of chest pain. Subsequently, they will be asked to comment on their interpretation of the items on the Rose Angina Questionnaire and to assess its relevance, acceptability and appropriateness to the target population. Participants will be asked to suggest alternatives to the current translations and to suggest additional relevant items.

Data will be analysed by the principal researcher in discussion with the bilingual project co-workers. Findings will be fed back to a sample of respondents for verification, and additionally validated by sharing the findings with community groups to enquire whether the wider community would concur with the findings.

---

**12. Proposed start date and duration of project**

The project studentship began in October 1999, and is funded for three years until September 2002. After ethical approval has been granted, additional funding will be sought, at which point project co-workers will be recruited, trained and the study begun. It is anticipated that the field work stage of the project (the interview study and analysis) will be completed by October 2001.

---

**13. Study design (e.g. Randomised Controlled Trial, cohort, case control, epidemiological analysis)**

This project will use a qualitative methodology as outlined in Section 11.

---

**14. Size of the study (including controls)**

Will the study involve:

(a) Human Subjects *Yes*

i) How many patients will be recruited?

The GP will contact 300 participants by letter to give their consent for their contact details to be released to the researchers. Those who give consent will be contacted for a brief telephone screening interview; 60 of these participants will then be selected to take part in the interview study.

ii) How many controls will be recruited?

N/A

iii) What is the primary end point?

**SECTION 3****Recruitment of subjects****16. Local Recruitment of Subjects****a) How many subjects are being studied within Lothian?**

300 possible brief telephone contacts (probably much less- participants will be sampled until the first 20 in each linguistic group meet the selection criteria); 60 semi-structured interviews

**b) Are any of these subjects involved in existing research or have been involved in any recent research in the last six months?**

Not to the researchers' knowledge.

*If yes, please justify their use in this project*

N/A

**c) Will any of the subjects involved be in a dependent relationship with the researcher?**

No

*If yes, please ensure you comply with local recruitment arrangements*

**d) Will any of the subjects involved be medical students?**

No

*If yes, please obtain signed agreement of the Dean of the Faculty of Medicine:*

Signature the of Dean of the Faculty of Medicine  
or equivalent if medical students are research subjects: .....

**17. How will the subjects in the study be:****a) selected?**

Before the study commences, the applicant will liase with community representatives and groups such as the Racial Equality Council, to discuss the project and gain feedback and community approval.

General practices known to have a sizeable number of ethnic minority patients from the groups (Punjabi and Cantonese) to be studied will be approached and asked for their co-operation in the study. Initial discussion by Professor Bhopal (the research supervisor) with general practitioner colleagues has shown interest in this type of research. It is hoped that sufficient numbers of Punjabi, Cantonese and English speakers can be obtained from the register of a single general practice, although more than one general practice register will be accessed if this proves not to be the case.

Patients will be sampled from the practice register by a combination of name searching, a method demonstrated to work for both Chinese and South Asian populations, and practice staff's knowledge of the ethnic origin of the patient. All sampled patients will be over 45 years of age. Approximately 100 people, stratified by age (decade groups) and gender, will be selected from each ethnic group. *Researchers will have no access to patients' contact details or any identifiable information until after the General Practitioner has informed them of the study and gained consent for their address and telephone number to be disclosed.*

The sample list will be screened by practice doctors to exclude those sampled patients who have previously stated their unwillingness to take part in any research or those who are too sick to participate.

**b) recruited?**

The researchers and practice staff will collaborate in selecting a sample of participants from each ethnic group (using only their names and ages and no other identifiable information). Having sampled approximately 100 patients from each language group, a letter (see attached) will be sent by the General Practitioner to the patient informing them of the study requesting consent to release their contact details to the researchers for a brief telephone screening interview. The letter will attach a patient information sheet (see attached) explaining the nature of the study, the confidentiality and anonymity of the telephone calls and the interviews, and their right to withdraw from the project at any time. The letter will also include a refusal form (see attached) indicating the patient's refusal to allow the GP to disclose their contact details, which the patient can return to the researcher if they wish to have no further involvement in the study.

Using randomised age and gender stratified lists of those willing to be telephoned, the applicant and bilingual project co-workers will begin to contact the selected participants by telephone two weeks after sending the letter, and ask them a small number of screening questions. These questions will deem the suitability of the participant for the interview study (see below for selection criteria), such as their answers to one question about chest pain, their preferred language, and their willingness to be interviewed face to face in more depth. On the basis of their answers, the participants will be asked whether they are prepared to participate in a longer interview in their own home, if convenient. We will then arrange an interview time for the first twenty participants from each ethnic group who fulfil the inclusion and exclusion criteria and who agree to be interviewed further.

**c) what inclusion criteria will be used?**

For telephone contact:

- Age 45 years or over
- 50 men and 50 women from each of the following ethnic groups:
  - Indian/ Pakistani ethnic group (Punjabi speakers)
  - Chinese ethnic group (Cantonese speakers)
  - White British ethnic group (English speakers)

For interview study from above sample contacted by telephone:

- From each ethnic group:
  - 10 male, 10 female
  - stratified by age
  - 5 of each gender having responded "yes" to the telephone question "Have you ever had any pain or discomfort in your chest?", 5 of each gender having responded "no" to the same question
- Preferred language: Punjabi or Cantonese in the South Asian or Chinese ethnic minority groups respectively

**d) what exclusion criteria will be used?**

As indicated above, patients below the age of 45 will not be contacted. The prevalence of both chest pain and angina is likely to be higher in people above 45 years of age. Additionally, in the ethnic minority samples, people above the age of 45 are more likely to cite the ethnic minority language as their preferred language. These are the people for which it is important to have accurately translated and adapted versions of the Rose Angina Questionnaire for use in epidemiological surveys. Therefore, those from the ethnic minority groups who are contacted by telephone and indicate that their preferred language of response is not Punjabi or Cantonese will be excluded. This study is concerned with the linguistic expression of chest pain and its effect on the validity of the current survey instrument, the Rose Angina Questionnaire.

Those who have previously indicated their unwillingness to take part in any research will be excluded, in addition to those refusing consent for the GP to disclose their contact details to the researchers. Additionally, any participants identified by their GP as being unfit to take part (for example those with forms of physical or mental illness which would place a strain on the patients or complicate the enquiry) will be excluded.

---

18. How will the control subjects group (if used) be: *(Type N/A if no controls)*

a) selected?

N/A

b) recruited?

N/A

c) what inclusion criteria will be used?

N/A

d) what exclusion criteria will be used?

N/A

---



---

**19. Is written consent to be obtained?**

Yes

*If yes, please attach a copy of the consent form to be used.*

Refusal and consent forms attached (one refusing consent for the GP to disclose contact details to the researchers for the purposes of a brief telephone screening interview, one giving consent to be interviewed).

*If no written consent is to be obtained, please justify.*

N/A

---

**20. How long will the subject have to decide whether to take part in the study?**

*If less than 24 hours please justify.*

The participant will have two weeks to return the refusal letter before being telephoned. If the patient agrees to the GP releasing their contact details in order to be telephoned, and if they meet the selection criteria after the telephone screening interview, they will be asked if they would be prepared to take part in a longer interview. If they agree, an interview time will be decided upon, probably within the next week or fortnight following telephone contact. Upon arrival, the participant will be asked to sign a consent form. So from initial informative letter to interview, the participant may have up to four weeks to decide whether or not to be interviewed, and three opportunities to decline involvement during that time.

---

**21. Please attach a copy of the written information sheet or letter to be given to the subject.**

*(See Guidelines page 3 and Appendix A.)*

Participant information sheet and letter attached

*If no Information Sheet is to be given, please justify.*

N/A

---

**22. Have any special arrangements been made for subjects for whom English is not a first language?**

Yes

*If yes, give details.*

Bilingual project co-workers will be recruited and trained to carry out the telephone calls and interviews in the participant's language (Punjabi or Cantonese). The participant information sheet and consent forms will be translated into Punjabi and Cantonese for use with participants from these linguistic groups.

*If no, please justify.*

N/A

---

**23. Will any of the subjects or controls be from one of the following vulnerable groups?**

Children under 16

People with learning difficulties

Unconscious or severely ill



**31. What particular ethical problems or considerations do you consider to be important or difficult with the proposed study?**

*Please give details.*

The main ethical concern is that of patient consent. The researchers will initially work in close partnership with the General Practice staff in order to scan their registers for age and gender stratified lists of names from each ethnic group. However no identifying patient information will be disclosed at this point to the researchers. The GP will then contact the patient informing them of the study and asking for consent to give the patient's contact details to the researchers. (see attached patient letter, participant information sheet and refusal form). If the patient does not refuse consent for their contact details to be disclosed, the researcher will contact them by telephone and explain that the study is being done by the University in association with the General Practice. If, after the brief telephone interview, the participant agrees to take part in a longer face-to-face interview, they will sign a consent form. At all stages the researchers will treat any patient information as strictly confidential.

Another ethical concern for this study is the information given to the participants about the nature of the project. Although this research is particularly interested in the perception and expression of chest pain, this is not specifically mentioned in the study title given to the participants, or emphasised in the participant information sheet and letter. Instead, we have referred to the study in its broader sense as "your understanding of health problems" and have embedded the information and questions about chest pain amongst questions about other symptoms such as indigestion, pain on taking exercise, leg pain etc. This is not an attempt to be deliberately misleading, and indeed questions will be asked about some general health perceptions, beliefs, and symptoms other than an exclusive focus on chest pain. However we deliberately did not stress the focus on chest pain, or use the word angina, in order to avoid evoking connotations of, or preconceptions about, heart disease that may distort the participants' responses or cause anxiety.

Another ethical consideration is that of confidentiality of information. This study has strict procedures to ensure confidentiality and consent, including rigorous training of the bilingual project co-workers.

An additional ethical issue might arise if an interviewee appeals to the applicant or a project co-worker for advice on medical or personal matters. In this case, if an interviewee asks for further advice or information about health, or indicates that they are experiencing some health problems, the interviewer will advise them to contact their GP. If the advice asked for is of a non-medical nature, the interviewer will advise them to contact an appropriate community support group.

---

**32. Will information be given to the patient's General Practitioner?** *No*

Please note: permission should always be sought from research subjects before doing this.

*If yes, please enclose an information sheet/letter for the GP.*

*If no, please justify:*

This study will stress confidentiality of information shared by the participant and none of this information will be fed back to the General Practitioner unless the participant requests this. (An anonymised summary of the research will be made available to the General Practitioner but no personal information or details will be identifiable from such a summary.)

---

**33. If the study is on hospital patients, will permission of all consultants whose patients are involved in this research be sought?** *N/A*

*If no, please justify:*

N/A

OUR REF: LREC/2000/3/19

YOUR REF:

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Lisa Hanna  
Public Health Sciences  
University of Edinburgh  
Medical School, Teviot Place  
Edinburgh EH8 9AG

13 November 2000

Dear Ms Hanna,

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

Thank you for submitting the above protocol for ethical approval. The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee has discussed this protocol and has agreed that it is prepared to grant ethical approval subject to the following amendments, delegating authority to the Chairman to approve them on receipt:

- Following considerable discussion, the Sub-Committee agreed that the letter to subjects should be reworded so that they had to give active consent to be considered for the study. It was agreed that if there were difficulties in recruiting subjects to the study, the sub-committee would be willing to reconsider this issue.

**Once these amendments have been received by me and approved by the Chairman a formal Certificate of Approval will be issued. Only then can management approval be given and the research proceed.**

The next meeting of the Sub-Committee will be held on 1 December 2000. It would be appreciated if the required amendments could be available prior to that date.

Should you have any queries regarding the above, please contact myself on the number below.

Yours sincerely

**ANNETTE HARRIS**

Administrator

Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee

LOTHIAN HEALTH BOARD

LOTHIAN RESEARCH ETHICS COMMITTEE

DEACONESS HOUSE

148 PLEASANCE EDINBURGH EH8 9RS

TELEPHONE: 0131 536 9000 DIRECT DIAL: 0131 536 9050

FACSIMILE: 0131 536 9346

E-MAIL: [annette.harris@lhb.scot.nhs.uk](mailto:annette.harris@lhb.scot.nhs.uk)

**Ref: LREC/2000/3/19**

13<sup>th</sup> November 2000

Dr Alan Cummings,  
Chairman, Healthy Volunteer Studies/ Public Health Medicine Research Ethics Sub-Committee  
Lothian Research Ethics Committee  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS

Dear Dr Cummings

**Re: The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

Further to my discussion with the Healthy Volunteer Studies/ Public Health Medicine Research Ethics sub-committee on Friday 3<sup>rd</sup> November, I write to confirm that we are willing to follow the advice of the sub-committee and will modify our protocol to include gaining express consent from potential participants prior to disclosure of their contact details by the GP. Please find enclosed the modified letter to the participant from their GP, the participant information sheet and the express consent form.

As also suggested, we will return to the sub-committee to discuss alternatives to express consent if this process does not yield an adequate response rate.

Yours sincerely,

Lisa Hanna  
PhD student

Enc: 3

**Letter of invitation to research participants**

**General practice headed notepaper**

Address

Date

Dear (name of patient)

**Re: Your understanding of health problems**

Understanding how people from different communities understand and speak about certain health problems (such as indigestion, discomfort in the chest, or pain when taking exercise) is really important in order to improve health and health care for all ethnic groups. Our general practice is involved in a study about ethnicity and health carried out by Lisa Hanna from the University of Edinburgh, under the guidance of Professor Raj Bhopal and Dr Sonja Hunt. They are interested in your understanding of certain health problems and why you go to the doctor.

We are writing to ask whether you give consent for us to release your name, telephone number and address to the researchers at the University of Edinburgh. If you agree, someone would phone you at home to ask you a few questions about the language you prefer to speak and about your experience of certain health problems, if any. They may then ask whether you would be willing to help further with the study. Helping would mean talking to someone who speaks your language either in your own home or another convenient place, for about an hour.

We have enclosed an information sheet giving you more details about the study to help you decide. Whatever you decide about helping with the study, your care from us at your practice will not be affected. If you permit us to reveal your contact details we would be grateful if you would complete and return the enclosed consent form as soon as possible.

If we receive your consent form, we will allow the researchers to have access to your name, address and telephone number and to contact you by telephone. We stress that the researchers will treat this information as strictly confidential. We will not be giving the researchers any medical information about you.

Your help in this study would be very much appreciated.  
Thank you.

Yours sincerely,

GP's name

NOTE: THE FOLLOWING INFORMATION SHEET WILL BE TRANSLATED INTO PUNJABI OR CANTONESE AS APPROPRIATE. WHILST IN THIS VERSION, ALL ALTERNATIVES ARE INCLUDED (EG PUNJABI/ CANTONESE/ ENGLISH, NAMES OF CO-WORKERS ETC), THE FINAL TRANSLATED VERSIONS WILL INCLUDE ONLY THAT INFORMATION THAT IS PERTINENT TO THE SPECIFIC LINGUISTIC GROUP.

.....

### **Participant Information Sheet**

University of Edinburgh/ General Practice headed paper

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

Thank you for reading this.

## **YOUR UNDERSTANDING OF HEALTH PROBLEMS**

### *What is the aim of the study?*

This study aims to explore how people speaking different languages express their understanding of some common health problems, how they interpret certain questions about these health problems, and why they seek medical attention for these problems. It will involve speaking to a number of Punjabi speaking people, Cantonese speaking people and English speaking people to see if there are differences between them. The study will last for a further two years.

### *Who is organising and funding the research?*

The study is being done by Lisa Hanna, a doctoral researcher at Edinburgh University. Lisa is assisted by a Punjabi speaking project co-worker [name] and a Cantonese speaking co-worker [name]. The study is funded by a Medical Faculty Research Scholarship and by [additional funding details]. Your GP is not receiving payment for including you in this study. The study is supported by Professor Raj Bhopal and Dr Sonja Hunt at the University of Edinburgh.

### *Why have I been chosen?*

We want to in talk to people from different language groups about their experience and understanding of symptoms of ill-health. Your name has been selected from the list of South Asian/ Chinese/ British patients on the surgery's



register who are believed to speak Punjabi/ Cantonese/ English, and who are over 45 years of age. Altogether 100 people from each language group have been selected to be contacted initially by phone. From these about 20 people in each language group will be asked to take part in a longer face-to-face discussion.

### *Do I have to take part?*

It is up to you to decide whether or not you want your doctor to give us your telephone number. If you do decide to allow us to telephone you to ask you a few questions, you can return the signed consent form to your GP, but can withdraw at any time. After we have telephoned you we may ask you to take part in a longer discussion. Again, you are free to refuse if you want to. If you agree to take part in this interview, you will be given another consent form to sign before the interview. However you may still stop the interview at any time and you need not answer any question you'd rather not. Whatever you decide, your current or future care from your doctor will not be affected in any way.

### *What will happen to me if I take part?*

[Appropriate co-worker] would like to telephone you at home on one occasion to ask you which language you prefer to speak and a few simple questions about your experience of certain symptoms of ill-health. This telephone call should take up no more than five minutes of your time. Then you might be asked if [appropriate name] could visit you in your own home, if convenient, for a longer interview. This visit should last about an hour. We need to tape-record the conversation so that we have an accurate account of what has been discussed. If you agree, together we will arrange a convenient time for you to be interviewed. After this interview, you may be asked whether you would be prepared to talk to Lisa or [name of co-worker] again at a later date in order to check that you agree with our findings.

### *What happens to this information? Is it confidential?*

You will be asked to sign a consent form allowing your GP to give us your contact details so we can telephone you. If you then agree to take part in a longer interview, you will also be asked to sign a written consent form indicating your willingness to take part. Whilst your GP will be notified of your participation in the study, any information you share will be treated as strictly confidential. No information will be passed back to the practice or your doctor unless you request this to happen. The only person/ people who will know what you yourself have said is/are Lisa/ and [appropriate bilingual project co-worker].

If you are take part in the longer tape-recorded interview after being telephoned, you will not be identified by name either on the tapes or in any notes. Your name and any identifying details will be kept securely in a locked filing cabinet and will be destroyed at the end of the study in approximately two years time.

The results of this study will form a doctoral thesis by Lisa Hanna for the University of Edinburgh. This written work is likely to be completed in about two years time. A summary of the study will be available for you to read if you desire. A summary of the research will also be sent to the participating general practice and to the funding bodies at the end of the study. This work may be published so that people in the NHS and elsewhere can read it and improve future research on the health of different ethnic groups. In this and all other written reports your name is not mentioned and no-one will know from the reports what you have said.

*What are the benefits of taking part?*

Understanding how people from different communities understand and speak about health problems is really important in improving the health and health care of all ethnic groups. The information we get from this study may help us treat future Punjabi/ Cantonese/ English-speaking patients better.

*Who has reviewed this study?*

Lothian Research Ethics Public Health Medicine Sub-Committee have reviewed this study.

*Contact for further information*

You are welcome to contact Lisa, [Punjabi-speaking co-worker(s)] or [Cantonese speaking co-worker(s)] at the address or phone number given in the attached letter if you want further information at any time.

You are also welcome to contact Antonia Ineson, the Independent Adviser for the study, if you have concerns at any stage.

You may contact her at:

Health Promotion,  
Lothian Health,  
Deaconess House,  
148 Pleasance,  
Edinburgh  
EH8 9RS  
Telephone: (0131) 536 9425

Thank you for taking the time to read this information sheet. Please consider participating in this study. Your help would be much appreciated.

This information sheet is yours to keep.

Should you decide to participate in this study you will also be given a copy of your signed consent form to keep.

Date:

Version number:



NOTE: FORM TO BE TRANSLATED INTO PUNJABI OR CANTONESE AS APPROPRIATE

General Practice headed paper

EXPRESS CONSENT FORM (TO BE RETURNED IN ATTACHED STAMPED  
ADDRESSED ENVELOPE)

Name:

.....

Address:

.....

.....

.....

Telephone:.....

Date:.....

**Re: Your understanding of health problems**

I permit my GP to give my name, address and telephone number to the ethnicity and  
health researchers at the University of Edinburgh.

Signature:



OUR REF: **LREC/2000/3/19**

YOUR REF:

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Lisa Hanna  
Public Health Sciences  
Medical School  
Medical School, Teviot Place  
Edinburgh EH8 9AG

29 November 2000

Dear Ms Hanna,

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

Thank you for submitting the amendments or additional information requested by the Sub-Committee for the above protocol. The Chairman of the Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee has now agreed to confirm the Sub-Committee's ethical approval under its delegated authority. An official Certificate of Ethical Review is enclosed together with a list of members present at the meeting.

Under the terms of the Scottish Office Home and Health Department Guidelines on Local Research Ethics Committees this decision has been notified to the NHS body under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Research Ethics Sub-Committee and from whom you must obtain management approval before any work on the study can proceed.

Yours sincerely

**ANNETTE HARRIS**

Administrator

Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee

LOTHIAN HEALTH BOARD

LOTHIAN RESEARCH ETHICS COMMITTEE

DEACONESS HOUSE

148 PLEASANCE EDINBURGH EH8 9RS

TELEPHONE: 0131 536 9000 DIRECT DIAL: 0131 536 9050

FACSIMILE: 0131 536 9346

E-MAIL: [annette.harris@lhb.scot.nhs.uk](mailto:annette.harris@lhb.scot.nhs.uk)

## **LOTHIAN RESEARCH ETHICS COMMITTEE**

### **CERTIFICATE OF ETHICAL REVIEW**

**LREC Reference Number: LREC/2000/3/19**

**Title: The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

**Researcher: Ms Lisa Hanna**

The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee reviewed this proposed study and has agreed that it is ethical and appropriate to be carried out in the Lothian Area. This opinion encompasses all aspects of the application including the Patient/Subject Information Sheet and all other accompanying documentation provided.

The date of the meeting and the members present are shown on the attached sheet.

It is a condition of this opinion that you must obtain appropriate management approval from the relevant NHS body under the auspices of which the research is intended to take place before starting the study. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Local Research Ethics Committee. It is also a condition that you are required to notify the Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee, in advance, of any significant proposed deviation from the original protocol or application form. Reports to the Sub-Committee are also required once the research is underway if there are any unusual or unexpected results which raise questions about the safety of the research.

Researchers are also required to report on success, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the project among patients and volunteers.

Peter Reith  
Secretary  
Lothian Research Ethics Committee  
Medicine

Annette Harris  
Administrator  
Healthy Volunteer Studies/Public Health  
Research Ethics Sub-Committee

The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Standing Orders, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Membership List, Standing Orders and Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request.



Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

19<sup>th</sup> April 2001

Committee Administrator  
Healthy Volunteer Studies/ Public Health Medicine Research Ethics Sub-committee  
Lothian Research Ethics Committee  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS

Dear Sir/Madam,

**Research protocol LREC/2000/3/19: The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

I am writing to inform the chairman of the HVS/PHM Research Ethics Sub-committee of some minor amendments to the wording and format of the documents to be used in the above study. Following a pilot study, we have edited the documents for increased clarity and ease of understanding by participants. We have taken care whilst editing the original to ensure that the amended version does not omit any of the items required by the research ethics guidelines, and does not distort the content of the information given to the participant. No changes to research protocol are included in the amendments. The changes are as follows. Enclosed please find both the original documents submitted and the amended versions.

1. Title: The short title of the project, for participants, was originally "Your understanding of health problems". We have amended this to "Your understanding of pain and ill-health".
2. Participant information sheet: changes have been made to minimise passive sentences and complexity of wording to make the information sheet as simple as possible to read and understand by all participants, and for ease of translation into the ethnic minority languages. Again, we have taken care to follow the recommendations made by LREC in their guidelines.
3. Introductory letter: The letter from the General Practice has been edited for ease of reading and translation.
4. Express consent form: On the express consent form sent to their GP by patients who wish to take part in the study, we have omitted the original request for them to fill in their address. We consider this too much information for the patient to complete and think the response rate may

be higher should we only ask them to fill in their up-to-date telephone number and give consent for their GP to give this to us.

We would be grateful if you could let us know as soon as possible whether or not whether it is necessary to inform the Chairman of all such changes to wording and if so, whether these changes are acceptable.

We look forward to hearing from you.

Yours sincerely

Lisa Hanna

PhD student

(also on behalf of Professor Raj Bhopal and Dr Sonja Hunt, Project Supervisors, Community Health Sciences, University of Edinburgh)

Enc (6)

OUR REF: LREC/2000/3/19

YOUR REF:

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Lisa Hanna  
Public Health Sciences  
University of Edinburgh  
Medical School, Teviot Place  
Edinburgh EH8 9AG

15 May 2001

Dear Ms Hanna,

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina questionnaire.**

Thank you for submitting Amendment dated 19 April 2001 in respect of the above protocol. The Chairman of the Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee, acting under delegated authority, has agreed that the study may continue. This approval encompasses all aspects of the amendment including any changes necessary to the Patient/Subject Information Sheet and other accompanying documentation.

It is also necessary for you to notify any relevant NHS bodies from whom Management Approval for this study was obtained.

A condition of this approval is that you are required to notify the Sub-Committee, in advance, of any significant proposed deviation from the original protocol. Reports to the Sub-Committee are also required once the research is underway if there are any unusual or unexpected results which raise questions about the safety of the research.

In addition, researchers are required to report on success, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the project among patients and volunteers.

The Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Standing Orders, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Membership List, Standing Orders and Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request.

LOTHIAN HEALTH BOARD

LOTHIAN RESEARCH ETHICS COMMITTEE

DEACONESS HOUSE

148 PLEASANCE EDINBURGH EH8 9RS

TELEPHONE: 0131 536 9000 DIRECT DIAL: 0131 536 9050

FACSIMILE: 0131 536 9346

E-MAIL: [annette.harris@lhb.scot.nhs.uk](mailto:annette.harris@lhb.scot.nhs.uk)



Yours sincerely

**KATHERINE MCALLISTER**

Administrator

Healthy Volunteer Studies/Public Health Medicine Research Ethics Sub-Committee

cc    *Relevant Lothian NHS Trust(s)*

*University of Edinburgh Faculty of Medicine*

*University of Edinburgh*

*Medical School*

*Teviot Place*

*Edinburgh EH9 8AG*

✓





Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

27th August 2001

Committee Administrator  
HVS/PHM Research Ethics Sub-Committee  
Lothian Research Ethics Committee  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS

Dear Ms McAllister,

**Re: LREC/2000/**

Further to Lisa Hanna's recent telephone discussion with Dr. N Bateman, we would be most grateful if you could pass on this letter for discussion at the next HVS/ PHM research ethics committee meeting on 7<sup>th</sup> September. Lisa Hanna is available to attend the committee meeting and for reasons given below this is advisable.

We would like to update the committee on the success of the protocol agreed upon when ethical approval was granted to this study (the initial application form was submitted on 16<sup>th</sup> August 2000 and ethical approval was granted on 29th November 2000). This study aimed to interview ten men and ten women from each of three language groups (English, Punjabi and Cantonese) about their experience and understanding of pain, ill-health, chest pain and angina. The study aimed to assess the feasibility of using the Rose Angina Questionnaire in multi-ethnic epidemiological surveys, and also to increase awareness of a range of ethnic and linguistic experience in the health services in the light of the very high rates of CHD in South Asian populations and ethnic variations in cardiovascular disease.

The ethical committee's requirement of express consent

In order to obtain our interview sample of 60 participants, we requested ethical permission to use GP registers to identify people of European, Chinese and Pakistani origin. The ethical committee required that the first contact came from the GP to the patient. The patient was then to return a consent form to the GP permitting her/him to give us the patient's telephone number for subsequent contact. The ethical committee

required us to report on our experience and offered to consider the matter afresh should this approach yield poor response rates.

#### Response rates

The express consent option has yielded a remarkably low response rate amongst the ethnic minority sample, as shown in the following table. Extensive experience of health surveys in the UK has demonstrated that when contacted by telephone or face-to-face, the response rates in Britain's ethnic minority populations is as high, or higher, than in the white European origin populations.

General Practice	Number contact packs posted	Date of postage	Number of responses to date
A	50 English	31.5.01	20 (19 within fortnight after postage) (40%)
A	31 (Cantonese/English)	18.7.01	5 (16.1%)
A	31 (Urdu/English)	6.8.01	4 (12.9%)
B	90(Cantonese/English)	17.7.01	5 (5.6%)
C	42 (Urdu/English)	19.8.01	4 (9.5%)

This poor response in the ethnic minority groups despite the resources invested is certainly disappointing. Approaching, informing and involving General Practices has been a time-consuming process both for the researcher and the practice staff. Each contact pack sent to potential participants as identified by practice staff, has contained an information booklet and its translation, a letter and its translation signed by the GP, and a stamped addressed envelope enclosing the express consent form and its translation.

#### Possible explanations for poor response

The researcher carried out an initial phase of community outreach and visited many key community groups, key informants and community representatives and relevant organisations (e.g. the Equalities Unit at Edinburgh City Council, Lothian Racial Equality Unit, and the Minority Ethnic Health Inclusion Project) to gain comments on and support for the project. Many of the community representatives spoken to suggested that outreach work using gatekeeping groups or individuals is the best way to involve ethnic minority participants in research. It is also likely that initial verbal contact made by someone who speaks their language would be more efficient than postal contact in recruiting elderly ethnic minority participants, many of whom are illiterate, particularly in the Cantonese speaking group. A less likely explanation is that potential participants were no longer resident at the address held by the General Practice- only four contact packs were returned by the post office as addressee unknown.

### Findings from the interviews to date

Nine in-depth interviews have been carried out so far with ethnic minority participants (3 Punjabi-speaking men, 1 Punjabi-speaking woman, 4 Cantonese-speaking men, 1 Cantonese speaking woman) and ten with interviews with English-speaking participants (5 men and 5 women). Participants are very keen to assist in research and often mention that they are eager to do anything that will help their community. Interesting views are emerging concerning general health beliefs, behaviours and concerns, consultation behaviour, knowledge and understanding of angina and heart disease, and linguistic expression of general pain, discomfort and chest pain. In addition we have asked participants to comment on existing translations of the Rose Angina Questionnaire and whilst many of the elderly ethnic minority participants found this task difficult to comprehend, we have discovered a number of issues throughout this field work that impact on the development of cross-culturally valid epidemiological instruments. For example, the Cantonese version of the Rose Angina Questionnaire can not be administered as written to an illiterate elderly Cantonese speaker, as the written form of the language is meaningless if read orally. Hence the interviewer must translate into oral Cantonese, a process that has not been monitored in the past and could hence lead to a number of explanatory inter-interviewer biases.

### Options

We would be very grateful if the committee could consider granting ethical approval for one or, preferably, both of the following options to permit this project to develop onto a more successful footing.

1. With the General Practice's consent, our project workers to directly telephone the participants identified from each practice as being of Chinese or Pakistani origin without first obtaining express consent. Names and telephone numbers of potential participants to be released temporarily to project workers. The object of the telephone call would be to assess that invitations have been received, the project understood, and that the failure to reply implies a preference for non-participation. If this is not the case our project workers will explain the project and seek verbal consent to proceed.
2. We recruit interviewees through a combination of community groups, snowball sampling and project workers' community contacts. In fact, this option was suggested by the ethical committee at the meeting on 3/ 11/ 00.

### Need for urgency

1. We advertised widely throughout community channels and recruited, language tested, and employed four bilingual project workers to carry out interviews and assist with subsequent translation and analysis. Project workers received full training in the project's background, in interviewing skills and qualitative analysis. We are now in the position where the project workers have each carried out between 1 and 4 interviews already, but have no further potential participants to contact due to the poor response rate. Given the project workers' enthusiasm and commitment to their job, we are keen to provide them with sufficient work as promised.

2. This project is funded by a CSO small grant, which is ending in December 2001.
3. Time is of the essence in this doctoral project, given that the thesis needs to be completed by October 2002.

We would therefore be most grateful if the committee would consider permitting us to go ahead with either option outlined above. If neither option were acceptable we would be grateful if the committee could help generate alternative solutions. Lisa Hanna will stand-by to attend the meeting. Raj Bhopal is not available on that day but is willing to discuss matters with the committee prior to or after the meeting.

We look forward to hearing from you.

Yours sincerely,

Lisa Hanna  
PhD student

Professor Raj Bhopal CBE  
Bruce and John Usher Chair of Public Health

CC: Dr. N Bateman

OUR REF:

YOUR REF:



Ms Lisa Hanna  
PhD Student  
Public Health Sciences  
Dept of Community Health Sciences  
The University of Edinburgh  
Medical School  
Edinburgh EH8 9AG

Dear Ms Hanna

**Re: LREC/2000/3/19**

I refer to your letter dated 27<sup>th</sup> August 2001 which was considered by the HVS/PHM Research Ethics Sub-Committee at its meeting on 7<sup>th</sup> September 2001.

The decision of the Sub-Committee was as follows :

*The sub-committee agreed that the researcher may proceed with one of the following options;*

- *The GP may contact subjects using the practice's regular interpreter. However, this interpreter must not be the project worker. The researcher is not permitted to cold call subjects directly.*

OR

- *The researcher may use option 2 "We recruit interviewees through a combination of community groups, snowball sampling and project workers' community contacts. In fact, this option was suggested by the ethical committee meeting on 3/11/00."*

Please advise which option you select. I hope this response permits you to proceed with your project.

Yours sincerely

Liz Harden  
Administrator  
HVS/PHM Research Ethics Sub-Committee

cc: Professor Raj Bhopal CBE, Bruce and John Usher Chair of Public Health  
Dr N Bateman  
Lothian University Hospitals NHS Trust



Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

16<sup>th</sup> November 2001

Liz Harden  
Administrator  
HVS/ PVM Research Ethics Sub-Committee  
Lothian Research Ethics Committee,  
Deaconess House,  
148 Pleasance  
Edinburgh EH8 9RS

Dear Ms Harden,

**Re: LREC/2000/3/19**

In response to your recent letter regarding the above research project, I have selected the second option approved by the HVS/PHM sub-committee at its meeting on 7<sup>th</sup> September 2001. This option stated

*"We recruit interviewees through a combination of community groups, snowball sampling and project workers' community contacts. In fact, this option was suggested by the ethical committee meeting on 3/11/00."*

Please forward my thanks to the sub-committee for its approval.

Yours sincerely

Lisa Hanna  
PhD student



## **Appendix 5      Participant contact pack materials in Urdu, Chinese and English**

**NB: The materials shown are of the same content as those used throughout the study, but in slightly different format. When sent to participants, the letter from their GP and the form giving consent for their contact details to be released to researchers were printed on general practice-headed paper. The information sheets were printed professionally as double-sided A5 booklets on coloured paper, with the University of Edinburgh crest on the front cover. Punjabi and Cantonese participants were sent the documents in both Urdu or Chinese script respectively, and in English. The documents were placed in an A5 envelope with a stamped addressed envelope for the consent form to be returned to the practice.**



2001

Dear

**Re: Your understanding of pain and ill-health**

Understanding how people from different communities speak about pain and ill-health is important for the health and health care of all ethnic groups. Our general practice is involved in a study on this topic by Lisa Hanna, Professor Raj Bhopal and Dr Sonja Hunt from the University of Edinburgh. Full information about the study is given in the enclosed information booklet.

Would you be willing to give your name and telephone number to the researchers at the University of Edinburgh, or give consent for us to do so? If you agree, someone who speaks your language will telephone you to ask you a few questions about the language you prefer to speak and about your experience of pain and ill-health, if any. They may then ask whether you would be willing to help further with the study by talking to them, either in your home or the University, for about an hour.

Please read the enclosed information sheet giving you more details about the study to help you decide. Whatever you decide, your care from us at your practice will not be affected. **If you agree to take part, we would be grateful if you would complete and return the enclosed consent form in its pre-stamped addressed envelope as soon as possible.**

If we receive your consent form we will allow the researchers to contact you by telephone. We stress that the researchers will treat your contact details and any other information as strictly confidential. **We will not be giving the researchers any medical information about you.**

Your help in this study would be very much appreciated.  
Thank you.

Yours sincerely,

# *Your Understanding of Pain and Ill-health*

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like to know more.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

**Thank you for reading this.**

Information

## ***What is the aim of the study?***

This study will explore how people speaking different languages talk about pain and ill health. We will interview 20 English speaking people, 20 Cantonese speaking people and 20 Punjabi speaking people to see if there are differences between them. The results will be available in two years.

## ***Who is organising and funding the research?***

The study is being done by Lisa Hanna from Edinburgh University. Lisa is assisted by two Punjabi-speaking project workers and two Cantonese speaking project workers. Professor Raj Bhopal and Dr Sonja Hunt from Edinburgh University also work on this study. The study is funded by a Medical Faculty Research Scholarship and by the Scottish Executive. Your GP is not receiving payment for including you in this study.

## ***Why have I been chosen?***

We want to talk to people who speak different languages about their experience and understanding of pain and ill-health. Your name has been selected from the list of patients on the surgery's register who are believed to speak English and who are over 45 years of age. This information booklet is being sent to 100 people who speak English and we hope to interview 20 of these people.

## ***Do I have to take part?***

It is up to you to decide whether you want to give us your telephone number. If you do decide we can telephone you to ask you a few questions, please return the enclosed consent form to your GP. Some people may then be asked if they will take part in a longer discussion. If you agree, you will be given another consent form to sign before this longer interview. Whatever you decide, your current or future care from your doctor will not be affected in any way and you can withdraw at any time.

## ***What will happen to me if I take part?***

Lisa will telephone you to ask which language you speak and a few questions about your experience of pain and ill-health. This should take no more than five minutes. Then you might be asked to take part in a longer interview. This could be either in your own home or the University, as you prefer, and would last about an hour. We need to tape-record the conversation so that we have an accurate account of what has been said. We will arrange a time convenient to you.

## *What happens to this information? Is it confidential?*

You will not be identified by name either on tape or in any notes. Your name and any identifying details will be kept in a locked filing cabinet and will be destroyed at the end of the study in about two years. **Any information you give us will be treated as strictly confidential.** The only person who will know what you yourself have said is Lisa. Your GP will be told that you are taking part in the study but we will not tell the practice anything that you specifically have said. The information you give us will be combined with other anonymous information and a summary of these results will be sent to the practice and to the funding bodies. These combined results will also form part of Lisa's Ph.D. which will be finished in two years. We will also send you a summary of the study if you want. This work will be published so that people in the NHS and elsewhere can read it for the benefit of all communities. Remember, your name will not be mentioned.

## *What are the benefits of taking part?*

Understanding how people from different communities speak about pain and ill-health is very important in improving the health and health care of all communities. The information we get from this study may help us treat future English, Cantonese and Punjabi-speaking patients better.

## *Who has reviewed this study?*

Lothian Research Ethics Public Health Medicine Sub-Committee have reviewed this study.

## *Contact for further information*

If you want to know more at any time you are welcome to contact Lisa at:

Public Health Sciences  
University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone: (0131) 650 3230

You are also welcome to contact Antonia Ineson, the Independent Adviser for the study, if you have concerns at any stage.

You may contact her at:

Health Promotion  
Lothian Health  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS  
Telephone: (0131) 536 9425

**Thank you for taking the time to read this information sheet. Please consider taking part in this study and return the enclosed consent form to your GP. We are grateful for your help.**

This information sheet is yours to keep.

If you decide to take part in the longer interview you will be given a copy of your signed consent form to keep.

Date: May 2001

Version number: 1E

### **CONSENT FORM**

(PLEASE RETURN TO US IN THE ATTACHED STAMPED  
ADDRESSED ENVELOPE)

#### **Re: Your understanding of pain and ill-health**

I permit my GP to give the information contained below to the ethnicity  
and health researchers at the University of Edinburgh and understand that  
they may telephone me to ask if I would be willing to take part in a longer  
discussion.

Signature:.....Date:.....

Name:.....

Telephone number:.....

محترم

ریفرنس: آپ کی تکلیف اور بیماری کے بارے میں سمجھ

یہ جاننا کہ مختلف کمیونٹی کے لوگ تکلیف اور بیماری کو کیسے بیان کرتے ہیں، ان کی صحت کے لئے اور صحت کا دھیان رکھنے کے لئے بہت اہم ہے۔ ہماری جنرل پریکٹس اس موضوع کے مطالعہ میں حصہ لے رہی ہے جس میں لیسا ہنا، پروفیسر راج بھوپال، ڈاکٹر سونیا ہنٹ جن کا تعلق یونیورسٹی آف ایڈنبرا سے ہے شامل ہیں۔

کیا آپ ہمارے تفتیش کار کو اپنا نام اور ٹیلی فون کا نمبر دینے کے لئے تیار ہیں یا اس کی اجازت دیتے ہیں؟ اگر آپ راضی ہیں تو آپ کی زبان بولنے والا آپ سے کچھ سوال پوچھیں گے کہ آپ کونسی زبان میں بات کرنا پسند کرتے ہیں اور آپ کی تکلیف اور بیماری کے تجربے کے بارے میں پوچھیں گے۔ پھر آپ سے یہ بھی پوچھ سکتے ہیں کہ آپ اور تفصیل میں ان سے بات کر کے دیگر مدد دینے کے لئے تیار ہیں کہ نہیں۔ ان سے تقریباً 1 گھنٹے کی بات چیت یا تو آپ کے اپنے گھر میں ہو سکتی ہے یا یونیورسٹی میں۔

برائے مہربانی اس مطالعہ پر دیا ہوا معلوماتی پرچہ پڑھ کر فیصلہ کریں۔ اس پریکٹس میں آپ کا کیا جانے والا علاج آپ کے فیصلے سے قطعاً متاثر نہیں ہوگا۔ اگر آپ حصہ لینا چاہیں گے تو ہم مشکور ہو گئے۔ ساتھ دیا گیا اجازت نامہ بھر کر ٹکٹ لگے ہوئے لفافے میں ڈال کر ہمیں جلد از جلد واپس کر دیں۔

اگر ہمیں آپ کا اجازت نامہ ملا تو ہم اپنے تفتیش کار کو آپ سے رابطہ قائم کرنے کی اجازت دیں گے۔ ہم اس بات کا آپ کو یقین دلاتے ہیں کہ آپ کی ہر بات نہایت رازداری کے ساتھ رکھی جائے گی۔ ہم اپنے تفتیش کار کو آپ کی صحت کے بارے میں کوئی تفصیل نہیں دیں گے۔

اس مطالعہ میں آپ کی مدد کے ہم مشکور ہو گئے۔

آپ کے خیر خواہ

# آپ کی تکلیف اور بیماری کے بارے میں سمجھ

معلومات

آپ کو ایک ریسرچ کے مطالعہ میں حصہ لینے کے لئے دعویٰ کیا جا رہا ہے۔ اس سے پہلے کہ آپ فیصلہ کریں۔ آپ کے لئے یہ جاننا ضروری ہے کہ یہ ریسرچ کیوں کی جا رہی ہے۔ اور اس میں کیا شامل ہے۔ برائے مہربانی وقت لگا کر دی گئی تفصیل دھیان سے پڑھیں۔ اور اپنے دوستوں، رشتہ داروں اور ڈاکٹر کے ساتھ بھی مشورہ کریں۔ اگر کوئی بات واضح نہیں اور آپ تفصیل جاننا چاہیں تو ہم سے ضرور رابطہ قائم کریں۔

کنزنیو مرفار۔ سنکس ان ریسرچ نے ایک پروجیکٹ کیا ہے جس کا عنوان "میڈیکل ریسرچ اور آپ" ہے، یہ پروجیکٹ آپ کو میڈیکل ریسرچ کے بارے میں دیگر تفصیلات دیتی ہے اور کچھ سوالوں کو دیکھتی ہے جو شاید آپ پوچھنا چاہیں۔ ایک کاپی London NI6 0BW, PO Box 1365, CERES سے حاصل کی جاسکتی ہے۔

اس کتابچہ کو پڑھنے کا شکریہ۔



اس مطالعہ کا مقصد ہے؟

یہ مطالعہ اس بات کی جانچ پڑتال کرے گا کہ مختلف زبانیں بولنے والے لوگ بیماری اور تکلیف کے بارے میں کس طرح بات کرتے ہیں۔ ہم 20 پنجابی بولنے والے پاکستانی، 20 کنٹونیز بولنے والے اور 20 انگریزی بولنے والے لوگوں کا انٹرویو کریں گے اور دیکھیں گے کہ بیماری بیان کرنے کے طریقے میں کیا فرق ہے۔ نتیجہ دو سالوں میں دستیاب ہوگا۔

اس مطالعہ کا اہتمام کون کر رہا ہے اور مالی ذمہ داری کون لے رہا ہے؟

یہ مطالعہ ایڈمبراہ یونیورسٹی سے لیا جاتا ہے۔ لیسا کی مدد دو پنجابی بولنے والے اور دو کنٹونیز بولنے والے اہلکار کر رہے ہیں۔ پروفیسر راج پال اور ڈاکٹر سونیا ہنٹ بھی اس پر کام کریں گے۔ آپ کے ڈاکٹر کو آپ کے اس مطالعہ میں شامل ہونے سے کوئی پیسہ نہیں ملیں گے۔

مجھے کیوں شامل کیا گیا ہے؟

ہم مختلف زبانیں بولنے والے لوگوں سے ان کی تکلیف اور بیماری کی سمجھ کے بارے میں بات چیت کرنا چاہتے ہیں۔ آپ کا نام سر جری کے رجسٹر پر سے لیا گیا ہے جو کہ پاکستانی پنجابی بولنے والے ہیں اور جن کی عمر 45 سال سے زیادہ ہے۔ یہ کتابچہ 100 لوگوں کو بھیجا جا رہا ہے جن میں سے ہم 20 کا انٹرویو لیں گے۔

کیا مجھے لازماً حصہ لینا ہے؟

یہ آپ کا فیصلہ ہے کہ آپ ہمیں اپنا ٹیلی فون کا نمبر دینا چاہتے ہیں کہ نہیں۔ اگر آپ نے فیصلہ کیا کہ ہم آپ کو ٹیلی فون کر کے کچھ سوال پوچھ سکتے ہیں تو براہ مہربانی اجازت نامہ اپنے ڈاکٹر کو واپس کر دیں۔ کچھ لوگوں سے پوچھا جائے گا کہ کیا وہ تفصیلی بات چیت میں حصہ لینا چاہیں گے۔ اگر حصہ لینا چاہیں گے تو آپ کو اس تفصیلی انٹرویو سے پہلے ایک اور اجازت نامہ بھیجا جائے گا۔ آپ کا جو بھی فیصلہ ہوا۔ اس سے آپ کا مالی علاج اور آئندہ کا علاج قطعاً متاثر نہیں ہوگا اور آپ کسی وقت بھی اس مطالعہ سے نکل سکتے ہیں۔

اگر میں نے حصہ لیا تو مجھے کیا ہوگا؟

ایک پنجابی بولنے والا اہلکار آپ کو ٹیلی فون کرے گا اور آپ سے پوچھے گا کہ آپ کو کئی زبان بولتے ہیں اور کچھ سوال آپ کی تکلیف اور بیماری کے تجربے کے بارے میں پوچھے گا۔ اس پر پانچ منٹ سے زیادہ نہیں لگیں گے۔ پھر شاید آپ سے اور تفصیلی انٹرویو کے بارے میں پوچھا جائے گا۔ یہ انٹرویو آپ کے گھر پر ہو سکتا ہے یا یونیورسٹی میں۔ آپ کی مرضی کے مطابق ہوگا اور تقریباً ایک گھنٹے کے لئے ہوگا۔ ہم اس بات چیت کو ریکارڈ کریں گے تاکہ ہم اس بات چیت کا لفظ بہ لفظ ریکارڈ کر سکیں۔ ہم یہ وقت آپ کی مرضی کے مطابق مقرر کریں گے۔

## دیگر معلومات کے لئے رابطہ قائم کریں

اگر آپ دیگر معلومات حاصل کرنا چاہتے ہیں تو آپ کو اس پتے پر رابطہ قائم کرنے کے لئے مدعو کیا جاتا ہے۔

ہیلتھ سائنسز  
University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone: (0131) 650 3230

اگر کسی مرحلے پر کوئی پریشانی ہو تو آپ انسٹویشن میں، جو کہ خود مختار ایڈوائزرز سے بھی مندرجہ ذیل پتہ رابطہ قائم کر سکتے ہیں۔

ہیلتھ پروموشن  
Lothian Health  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS  
Telephone: (0131) 536 9425

اس معلوماتی کتابچے کو پڑھنے کا شکریہ۔ براہ مہربانی اس مطالعہ میں حصہ لینے کے بارے میں سوچیں اور شامل کئے ہوئے اجازت نامہ کو اپنے ڈاکٹر کو واپس بھیجیں۔ ہم آپ کی مدد کے مشکور ہیں۔

یہ معلوماتی ورق آپ کے رکھنے کے لئے ہے۔  
اگر آپ تفصیلی انٹرویو میں حصہ لینا چاہتے ہیں تو آپ کو ایک اور فارم بھیجا جائے گا۔

تاریخ: جون 2001  
ورژن نمبر: 1P

## ان معلومات کا کیا ہوگا؟ کیا یہ رازداری سے ہوگا؟

آپ کا نام ٹیپ پر کسی تحریر میں نہیں لکھا جائے گا اور آپ کا کوئی نام اور تفصیل جس سے آپ کی پہچان ہو سکتی ہے ایک بند الماری میں رکھی جائیں گی اور دو سال کے بعد جب مطالعہ اختتام پر پہنچے گا تو ان کو تلف کر دیا جائے گا۔ آپ ہمیں جو بھی معلومات دیں گے نہایت رازداری سے رکھی جائیں گی۔ ان معلومات کے متعلق واحد اس انٹرویو کرنے والے کو معلوم ہو گا جس کو آپ نے خود بتائی ہیں۔ ہم آپ کے ڈاکٹر کو بتائیں گے کہ آپ اس معلوماتی پروگرام میں حصہ لے رہے ہیں مگر یہ نہیں بتائیں گے کہ آپ نے کیا کہا ہے۔ جو معلومات آپ نے دی ہیں ان کو دیگر بے نام معلومات کے ساتھ شامل کیا جائے گا اور نتیجے کی مفصل رپورٹ ڈاکٹر کو اور جن اداروں نے مالی مدد دی ہے ان کو بھیجی جائے گی۔ آپ سب کی دی ہوئی معلومات ایسا کی پی ایچ ڈی کا حصہ بھی بنے گی جو کہ دو سالوں میں ختم ہوگی۔ اگر آپ نے چاہا تو ہم اس مطالعہ کی مفصل رپورٹ آپ کو بھیج دیں گے۔ اس کام کو شائع کیا جائے گا۔ تاکہ ایس ایچ ایس میں موجود لوگ اور کمیونٹی کے دیگر لوگ اس کو پڑھ سکیں اور اس سے فائدہ اٹھا سکیں۔ یاد رکھیں آپ کا نام نہیں لیا جائے گا۔

## حصہ لینے سے کیا فائدہ ہوگا؟

یہ جاننا کہ مختلف کمیونٹی کے لوگ تکلیف اور بیماری کو کیسے بیان کرتے ہیں۔ ان کی صحت کے لئے اور صحت کا دھیان رکھنے کے لئے بہت اہم ہے جو معلومات ہمیں ملیں گی اس سے ہم آئندہ پاکستانی پنجابی، کینیڈین اور انگریزی بولنے والے مریضوں کا بہتر دھیان رکھ سکیں گے۔

## اس مطالعہ کا کس نے کیا ہے؟

لوتھیان ریسرچ - سٹیکس ہیلتھ میڈیٹن سب کمیونٹی نے۔

## اجازت نامہ

(برائے مہربانی ساتھ دیئے گئے لفافے میں جس پر سٹیمپ لگا ہوا ہے اور پتہ لکھا ہوا ہے، ڈال کر واپس کریں)

ریفرنس: آپ کا تکلیف اور بیماری کا سمجھنا

میں اپنے ڈاکٹر کو اجازت دیتا/دیتی ہوں کہ جو معلومات نیچے دی ہوئی ہے وہ یونیورسٹی آف ایڈمنسٹریٹو سائنسز کے نسل اور صحت کے ریسرچرز کو دے سکتے ہیں۔ اور میں سمجھتا ہوں کہ وہ مجھے دیگر تفصیلی انٹرویو میں حصہ لینے کے لئے رابطہ قائم کر کے اجازت مانگ سکتے ہیں۔

..... دستخط ..... تاریخ .....

..... نام .....

..... ٹیلی فون نمبر .....

日期：2001

親愛的

關於：對病痛及生病的理解

理解不同社區人們對“病痛”及“生病”兩種說法的概念對於全體少數民族的醫療保健工作來說具有重要的意義。本診所已參與一項涉及此課題、由愛丁堡大學的 Lisa Hanna 女士、Raj Bhopal 教授和 Sonja Hunt 博士三人主管的研究活動。隨函所附的資訊冊內記錄了關於此項研究的詳細訊息。

您是否願意向上述研究人員提供您的姓名和電話號碼，或准許我們向他們轉達您的聯絡詳情？您若同意，將會有人用中文致電與您聯絡，詢問您平常使用哪種語言，並詢問您是否有過病痛、可曾生病。隨後，還會問您是否願意參加一項在您家裡或在愛丁堡大學進行的大約一小時的進一步訪問。

請閱讀所附的資訊冊，了解關於此項研究的更多訊息，以幫助您決定是否參與。無論您怎樣決定，本診所為您提供的保健服務均不會受到任何影響。如果您同意參加，請填寫隨函所附的同意表，並將其裝入已預付郵資的回郵信封，盡快寄回我處，我們深表謝意。

收到您的同意表之後，我們才會通知研究人員透過電話與您聯絡。請確信，研究人員會對您提供的一切資料嚴格保密。我們不會向研究人員提供與您有關的任何醫療資訊。

我們十分珍視您為本次研究提供的協助。

謝謝。

誠致敬意

## 對病痛及生病概念的理解

我們值此邀請您參加一項調查研究。在您作出決定之前，了解一下本次研究的目的以及研究活動所涉及的内容對您來說是很重要的。請抽空仔細閱讀下面的資訊，必要時可與朋友、親屬和您的家庭醫生（GP）討論其内容。如果有不明白的地方，或者想獲得更多的資訊，請與我們聯絡。

消費者調查道德準則監管局（Consumers for Ethics in Research 簡稱 CERES）出版了一份題為《參與醫療調查活動的消費者指引》（Medical Research and You）手冊。該資訊冊裡有關於醫療調查研究的詳細說明，並解釋了您可能有的疑慮的一些問題。您可以去函向該監管局索取這份資訊冊，地址是：CERES, PO Box 1365, London N16 0BW。

謝謝您閱讀本頁的資訊。

資訊冊

## 本次調查目的何在？

本次調查之目的在於發現講不同語言的人如何談論“病痛”和“生病”這兩個概念。我們將分別訪問 20 名講粵語、20 名講旁遮普語、和 20 名講英語的人士，看三組人員的描述是否不同。調查結果將於二年之後公佈。

## 誰是本次調查的組織者和贊助者？

愛丁堡大學 Lisa Hanna 女士負責這項研究工作。有兩名講粵語和兩名講旁遮普語的項目助手協助 Lisa 的工作。愛丁堡大學的 Raj Bhopal 教授和 Sonja Hunt 博士亦參與此項研究工作。研究經費由一份醫學研究獎學基金 (Medical Faculty Research Scholarship) 和蘇格蘭行政管理局 (Scottish Executive) 提供。您的家庭醫生不會因推薦您參加這項研究而獲得報酬。

## 為什麼會選中我？

我們想與講不同語言的人士談論對“病痛”和“生病”這兩個概念的感受和理解。您的名字從普通診所的註冊病人名單中挑出，因為您符合講粵語、年齡超過 45 歲的條件。這份資訊冊將發送給 100 名講粵語的人士，我們希望從中挑選 20 名受訪者來接受我們的訪問。

## 我必須參加嗎？

是否要向我们提供您的電話號碼，這完全由您來決定。如果您同意我們透過電話向您詢問幾個問題，請填寫隨函所附的《同意表》並將表格交給您的家庭醫生。某些受訪者隨後還會被問及是否願意參加時間較長的訪談。若同意，您會收到另外一份需要您簽署的同意表。簽署了該表格之後，便可參加進一步的訪談。無論您是否願意參加，您目前或將來的醫療服務均不會受到影響，即使決定參加，您也可以隨時撤回您的決定。

## 我若參加會怎麼樣？

講粵語的項目助手會致電詢問您講什麼語言，並問您幾個關於“病痛”和“生病”之感受方面的問題。詢問不會超過五分鐘。此後，可能還會問您是否願意參加時間較長的訪問。該訪問既可在您的家裡進行，亦可在大學裡進行，兩場所由您選擇，訪問時間大約一小時。訪問期間，我們需用錄音帶錄下我們之間的對話，以便準確記錄訪談內容。我們將安排一個適合您的訪問時間。

## 調查獲得的資訊會怎麼處理？ 能予以保密嗎？

無論是錄音帶還是筆記本上都不會記錄您的姓名。您的名字以及任何識別詳情都將保存在保密文件櫃裡，大約二年後在研究工作結束之時，予以消毀。您向我們提供的任何資料都將嚴格予以保密。只有訪問員一人知道您的談話內容。您的家庭醫生會被告知您將參加本次調查活動，但我們不會將您所談及的任何內容告訴診所。您提供給我們的訊息將與其他匿名資訊匯合在一起，研究結果之總結報告將送交診所和贊助機構。調查所得的綜合結果還將寫入 Lisa 的博士論文，該論文將於兩年之內完成。您若想獲得此項調查之結果概要，屆時我們可以為您寄去。研究報告將予以公佈，便於國家衛生局 (NHS) 官員及其他有關人員閱讀，以便能讓所有社區的民眾獲益。請放心，報告裡不會提到您的名字。

## 參加此項研究有何益處？

了解不同社區的民眾怎樣談論“病痛”和“生病”，這對於提高所有社區民眾的健康水平、改善保健服務都具有十分重要的意義。本項調查獲得的資訊能幫助我們更好地為講粵語、旁遮普語和英語的病人提供醫療服務。

## 此項研究得到什麼機構的審議？

Lothian 地區負責公眾健康調查道德準則的組委會 (Lothian Research Ethics Public Health Medicine Sub-Committee) 已審議了此項研究計劃。

## 索取更詳細資訊的聯絡地址

如欲獲得更詳細的資訊，歡迎隨時與愛丁堡大學醫學院的公眾保健系聯絡，地址及電話如下：

Public Health Sciences  
University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG  
電話：(0131) 650 3230

在參與研究活動的任何階段您若有疑慮，歡迎聯絡本次研究活動的獨立顧問 Antonia Ineson 女士。地址及電話：

Health Promotion  
Lothian Health  
Deaconess House  
148 Pleasance  
Edinburgh EH8 9RS  
電話：(0131) 536 9425

感謝您抽出時間閱讀這份資訊冊。請您考慮參加本次研究並填寫《同意表》，寄回您的診所。我們珍視您的協助。

這份資訊冊由您自己保管。

如果您決定參加時間較長的訪問，您會收到一份您已在上面簽了名的《同意表》的副本，此副本亦由您自己保管。

日期：2001 年 6 月

版本號：1C



## 同意表

(填好之後，請將表格裝入已預付郵資的回郵信封，寄回我處)

### 關於：對病痛及生病的理解

本人同意我的家庭醫生（GP）將以下資料轉交愛丁堡大學研究種族特點及保健課題的研究人員，並同意他們透過電話詢問我是否願意參與一項時間較長的訪問。

簽署：.....日期：.....

姓名：.....

電話：.....

## **Appendix 6**

### **Response rates in national and local studies examining tobacco and alcohol use in a range of ethnic groups**

(information extracted by Amanda Vettini,  
research associate, Public Health Sciences,  
University of Edinburgh, 2001)

Study	Overall response rates	African Caribbean or Caribbean	Indian/ Indian & E. African	Pakistani	Bangladeshi	Chinese	White or European	Irish
<i>BMEG 1992</i>	78%	-----	-----	-----	-----	-----	-----	-----
<i>BMEG 1994</i>	72%	60%	71%	79%	81%	-----	-----	-----
<i>FNS 1994</i>	-----	61%	74%	73%	83%	66%	71%	-----
<i>HLCE 1998</i>	70%	-----	-----	-----	-----	70%	-----	-----
<i>HSE 1999</i>	-----	55%	59%	60%	64%	62%	76%	65%
<i>Kohli, 1989</i>	-----	-----	95.3% (Asian)		-----	-----	92.8%	-----
<i>Cochrane &amp; Bal, 1990</i>	60.5%	-----	-----	-----	-----	-----	-----	-----
<i>Williams et al, 1993</i>	-----	-----	80.5%	-----	-----	-----	58%	-----
<i>Ahmed et al 1997</i>	-----	-----	-----	-----	46%	-----	-----	-----
<i>Bhopal et al 1999</i>	-----	-----	65.1% (S. Asian)		-----	-----	63.1%	-----
<i>White et al, 2001</i>	-----	-----	-----	-----	-----	59%	66.2%	-----
<i>Pearson et al, 2001</i>	-----	-----	-----	-----	85%	-----	-----	-----

**Appendix 7      Study proposal submitted to the Chief  
Scientist Office for additional funding,  
referees' comments and the researchers'  
response**

## **PROPOSED RESEARCH PROJECT:**

*Appendix 1*

### **The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire.**

#### **Introduction**

Coronary heart disease is the commonest cause of death in Britain's white and South Asian populations<sup>1</sup> and the second commonest in the Chinese (unpublished analysis by S Wild & R Bhopal). Within Britain's multicultural society, there are important, unexplained ethnic inequalities in coronary heart disease mortality.<sup>2,3</sup> Scotland's ethnic minority population in 1991 numbered 62, 634 or 1.3% of the total population, mostly (75%) with roots in South East Asia, particularly Pakistan, India and China. The Pakistani community is the dominant group in Scotland and the second largest community is the Chinese.<sup>4</sup> Edinburgh had about 10,000 ethnic minority residents in 1991. There were 1,171 black, 1176 Indian, 2625 Pakistani, 328 Bangladeshi, and 1940 Chinese people in Edinburgh.

Data from England demonstrating concerns about coronary heart disease and associated factors in all ethnic groups almost certainly apply in Scotland. Scotland therefore needs to contribute to research on this ethnicity and health theme. This project will help develop such a programme.

The Rose Angina Questionnaire<sup>5,6</sup> is the most common epidemiological angina screening tool used to assess coronary heart disease prevalence in a population. It is widely applied internationally and in cross-cultural research in Britain. The Newcastle Heart Project shown that this questionnaire performs inconsistently across ethnic groups.<sup>7</sup> There is, therefore, a need for an epidemiological angina screening questionnaire with greater cross-cultural validity.

Most questionnaires are developed in Western English-speaking populations and thus may be culturally biased. Inaccurately translated or modified language versions of such questionnaires in English can yield artefactual results. Often unrepresentative bilingual people have translated the adapted version, without involving monolingual lay people. Qualitative research is essential to good quantitative research in cross-cultural contexts.<sup>8</sup>

#### **Results of any pilot studies**

The Newcastle Heart Project (NHP) researchers, including the first applicant, assessed the performance of the Rose Angina Questionnaire in their sample of South Asian and European participants by analysing the Rose questionnaire outcome and its agreement with a doctor's diagnosis of angina and ECG measurements indicating heart disease.<sup>7</sup> A similar quantitative analysis on the NHP sample of Chinese participants is under way and will inform the proposed study.

#### **Aims of the proposed project**

- To develop an understanding of the perception, interpretation, significance and expression of chest pain in three different linguistic groups: Punjabi, Cantonese and English speakers.
- To assess the need for, and feasibility of, modifying the Rose Angina Questionnaire to produce an angina measurement tool valid for use in an ethnically diverse UK population.

#### **Research questions**

- Do Punjabi, Cantonese and English speakers differ in the ways they perceive, interpret and express chest pain?
- Are the translations of the Rose Angina Questionnaire in each language, as developed by the Newcastle Heart Project, equally appropriate, valid, acceptable and relevant to lay people from that linguistic group? Also, do they interpret the questions in the same way?

#### **Methods, expertise available, statistical power**

Meaning, perception and experience are best investigated, at least initially, by a qualitative approach. Hence, the issue of statistical power does not apply. We will conduct semi-structured interviews with people above 45 years of age, exploring people's perceptions and expressions of chest pain, and their assessment of the Rose Angina Questionnaire translations. This age group is chosen because the prevalence of both chest pain and angina is likely to be higher in people above 45 years of age and in the Punjabi and Cantonese speaking samples, people above the age of 45 are more likely to

prefer to speak their own language. Hence they have the greatest need for accurately translated and adapted versions of the Rose Angina Questionnaire.

#### *Sampling and recruitment of study participants*

We will recruit a few General Practices in Edinburgh known to have a high number of the Punjabi and Cantonese speakers. Early dialogue with General Practices has been supportive. Using a combination of a name search method, known to be effective in identifying Chinese and South Asian ethnic minority populations<sup>9-11</sup>, and the knowledge of practice staff, we will identify from patient registers potential participants from each linguistic group. We aim to obtain a sample of 100 people over 45 years (50 men, 50 women) from each of three linguistic groups (Punjabi, Cantonese and English) for initial telephone contact by a project worker with appropriate language skills. We will select only participants identified by their GP as being fit to take part. At telephone contact, we will ask some preliminary questions to select a sample of 10 male and 10 female participants from each linguistic group for interview. We will choose ethnic minority participants whose preferred language of response is Punjabi or Cantonese. From each sex and linguistic group, five will have responded "yes" and five "no" to the question "Have you ever had any pain or discomfort in your chest?" Our final interview sample will be 60 participants, 20 from each linguistic group.

#### *Data collection*

Project workers will have uniform training and will conduct the interviews in the appropriate language, in a location acceptable to participants, preferably their own homes. We will tape record the interviews. The interviews will explore the participants' experience and perception of chest pain. We will ask participants to comment on their interpretation of the items on the Rose Angina Questionnaire to assess their relevance, acceptability and appropriateness to them. We will ask participants to suggest alternatives to the current translations, to suggest possible additional items, and, if bilingual, to comment on the quality of the translation.

#### *Data processing and analysis*

The objective of the analysis is to investigate how the construct of chest pain is expressed linguistically and conceptually within each ethnic group, and to assess the lay participants' agreement with the previous translation of the Rose Angina Questionnaire. We will collate suggested modifications of the existing versions of the Rose Angina Questionnaire.

The researcher, Lisa Hanna (LH), will analyse the interviews conducted in English. For interviews in other languages, the interviewer and a second bilingual project worker will together extract relevant issues from the tapes and agree on an English equivalent (or its absence). LH and the project worker will then discuss the results. If appropriate, we may use a qualitative software package (such as NUD\*IST), although we have yet to ascertain whether such packages are relevant for this type of material concerning different languages, ethnicity, and health.

Subsequently, we will convene discussions with both groups of professionals and lay representatives of all three ethnic groups, to discuss the relevance, applicability and suggested translation of each item on the Rose Angina Questionnaire cross-culturally, and identify items that (i) are not equivalent across the groups (ii) are specific to each group. The groups will confer and agree on changes, if any, that ought to be made to the existing version of the Rose Angina Questionnaire. We will feedback for comment any new or amended items that emerge to a selected sample of respondents, and to community groups. We will, therefore, assess face and content validity of the modified versions of the angina questionnaires as part of this adaptation process.

#### *Ethical issues*

Ethical approval for this study has been sought from Lothian Research Ethics Committee.

#### *Expertise available*

The applicants have wide experience in cross-cultural epidemiology. The first applicant is currently developing a multiethnic cardiovascular research programme with Dr Sushmita Wiebe as research associate. Dr Sonja Hunt is an experienced social epidemiologist and qualitative researcher with wide expertise in working with cross-cultural questionnaires. The researcher, Lisa Hanna, is a



Ph.D. student working closely with Professor Bhopal's team. Contacts and colleagues include the Newcastle Heart Project research team and the research team at the University of Newcastle currently working on a CRC funded qualitative project exploring smoking in South Asians. Within Edinburgh, we have links to the Scottish Ethnic Minorities Research Unit and the Minority Ethnic Health Inclusion Project. We are also working on a Scottish Office-funded project on the use of tobacco and alcohol questionnaires in ethnic minorities.

#### **Timetable (October 2000- December 2001)**

We have applied for ethical approval from LREC and are currently recruiting general practice(s) to the study. Once ethical approval has been granted LH will begin the study on the English-speaking group. Once this proposal is granted, we will recruit, select and train bilingual project workers and begin the study of the Punjabi and Cantonese samples in January 2001. We aim to complete the selection process, interviews, analysis and feedback to participants and to community groups and health experts by the end of December 2001.

#### **Existing facilities**

The researchers are based at the University of Edinburgh Department of Public Health Sciences and will continue to use their existing office and computer facilities at this site for this study.

#### **Justification of requirements**

##### **STAFF AND INDIRECT COSTS**

Project workers will be employed on a casual basis per completed interview. There will therefore be no University overheads. These costs are given under the heading "Other" below.

##### **CONSUMABLES: £150**

We will require one tape recorder to tape the interview for subsequent analysis. Five people will be conducting interviews; if more tape recorders are required, we will use departmental equipment.

##### **TRAVEL: £435**

Project workers will be carrying out the interviews at participants' homes to allow participants to feel comfortable and speak freely outwith a medical environment. We have assumed that half these journeys will be made by bus, but have allowed that half may be made by taxi depending on the time of interview or the residential area visited. Two visits per participant are required, one for interview and another to verify findings. This respondent verification is vital to check that the analysis has not distorted the individual's perspective. Lisa Hanna's travel costs cover her visits to the English speaking sample to carry out interviews and visits to an estimated half of the ethnic minority participants to ask them about their experience of being interviewed, if their English skills are sufficient. In addition, we have included travel costs for those participants who prefer to be interviewed outside their own homes, for example in the University or the General Practice. We have estimated that one third of participants (20) may choose this option, and assumed that half will be able to journey by bus and half may require taxis.

##### **OTHER: £ 8415**

To do cross-cultural research on how concepts are expressed linguistically and culturally in different ethnic groups, the language of research must be the language of the researched group. Thus, this project requires bilingual co-workers with appropriate linguistic and cultural skills to carry out valid interviews, and to assist in the interpretation and analysis of data. The major costs for this project therefore are to employ adequately skilled project workers. The experience of colleagues from the University of Newcastle suggests that before appointing people to bilingual project worker posts, it is crucial to formally test their language, interpretation and translation skills. We have therefore included an estimate for such tests, which would include conducting a mock interview in Punjabi or Cantonese, relating responses in English, and an oral translation from tape. After the project workers have been appointed, they will take part in a two-day training session to ensure thorough knowledge of the project and to develop appropriate interviewing skills. We have included costings for the time taken by project workers to initially screen for potential participants by a brief telephone interview, in



addition to the cost of the calls. LH will contact the English speaking sample so only the cost of the telephone calls will be required for this linguistic group.

Postage and printing costs for the participant contact letter, information packs (3 pages describing the project) and consent/ refusal forms for return in a stamped addressed envelope are included in the costings. Lothian Research Ethics Committee requires that we provide all information to the ethnic minority participants in English and the ethnic minority language. We therefore include the cost of translation of these documents by a professional translation service.

A sufficiently rigorous research process for the ethnic minority sample will require 11 hours of paid time per participant (interview (1 project worker x 1 hour)+ listening to tapes and extraction of issues (3 hours x 2 project workers = 6 hours) + discussion with LH (2 hours x 2 project workers = 4 hours) + feedback to participants (1 hour x 1 project worker)). LH will contact English-speaking sample and conduct English-speaking interviews so there will be no costs for interviews with this linguistic group other than travel costs.

After the interview study, we have estimated that each of the four project workers may spend an additional five hours involved in community liaison discussion groups and attending multi-ethnic discussions with community representatives and health professionals to compare results across the linguistic groups studied.

### **TOTAL COSTS: £9000**

### **Research outcomes**

This project will contribute to the development of a cross-culturally valid measure of angina for use in future multi-ethnic epidemiological surveys. It will also lead to an increased awareness of how chest pain is perceived and expressed in three ethnic groups. Such information may help to achieve greater responsiveness to a range of ethnic experience in the health services.

Outcomes of this research will be of relevance to current NHS and Scottish Executive initiatives. It will provide valuable information on the conduct of participative research with ethnic minorities, and increase knowledge concerning the challenge of cross-cultural comparability in survey research. The study will contribute to assessing health needs of ethnic minorities and the delivery of ethnically appropriate health care and the detection of coronary heart disease both in primary care and on a population survey basis.

### **Dissemination**

The information arising from this study will form part of the researcher's doctoral thesis. We will circulate results to community groups and general practices in Edinburgh. We will submit manuscripts for publication in peer-reviewed journals, and will submit abstracts to at least one public health epidemiology conference and one medical sociology conference.

### **Key references**

1. Wild S, McKeigue P. Cross sectional analysis of mortality by country of birth in England and Wales, 1970-1992. *British Medical Journal* 1997;**314**:710.
2. Balarajan R. Ethnicity and variations in mortality from coronary heart disease. *Health Trends* 1996;**28**:45-51.
3. Bhopal R, Unwin N, White M, Yallop J, Walker L, Alberti KGMM *et al*. Heterogeneity of coronary heart disease risk factors in Indian, Pakistani, Bangladeshi, and European origin populations: cross sectional study. *BMJ* 1999;**319**:215-20.
4. Dalton, M. and Hampton, K. Scotland's ethnic minority community 1991. A census summary.

5. Rose G. The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organisation* 1962;**27**:645-58.
6. Rose GA, Blackburn H, Gillum RF, Prineas RJ. Cardiovascular survey methods. Geneva: WHO, 1982.
7. Fischbacher, C. M., Bhopal, R., White, M., Unwin, N., and Alberti, K. G. M. M. The comparative performance of the Rose angina questionnaire in South Asian populations. *Journal of Epidemiology and Community Health* 54(10), 786. 2000.
8. Hunt S. Cross-cultural issues in the use of quality of life measures in randomized controlled trials. In Stagnat M, Hays R, Fayers P, eds. *Quality of Life Assessment in Clinical Trials*, Oxford University Press, 1998.
9. Harland J. Identifying a representative sample of UK Chinese for epidemiological research. *UK Society for Social Medicine* 509.
10. Coldman AJ, Braun T, Gallagher RP. The classification of ethnic status using name information. *J.Epidemiol.Comm.Health*. 1988;**42**:390-5.
11. Nicholl A, et al. Accuracy of using surnames and forenames in ascribing Asian ethnic identity in English populations. *Journal of Epidemiology and Community Health* 1986;**40** :364-8.



## SCOTTISH EXECUTIVE

---

Health Department  
Chief Scientist Office

Professor Raj Bhopal  
Public Health Sciences  
University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh  
EH8 9AG

St Andrew's House  
Regent Road  
Edinburgh EH1 3DG

Telephone: 0131-244 2254  
Fax: 0131-244 2285  
Jennifer.waterton@scotland.gsi.gov.uk

Your reference  
Our reference: CZG/3/2/48

Date: 15 December 2000

Dear Professor Bhopal

**The challenge of cross-cultural comparability in survey research: a case of the Rose Angina Questionnaire**

I have now received referees assessments on your small grant application (enclosed). You will see they have identified a range of issues which require further consideration.

I look forward to hearing your responses to the points raised by referees.

Yours sincerely

**JENNIFER WATERTON**  
Research Manager

This is an interesting and potentially useful study. I would be supportive of the project but concerned about it at two levels, although both concerns can be remedied. The team are clearly highly appropriate for the study.

First, the study does not seem to complete the validation process. I appreciate the point that validating an instrument is a matter of degree, but it would seem that the researchers propose to check the RAQ against the views and perceptions of the two specified ethnic groups, which is entirely appropriate. They then plan to accommodate any necessary changes to the tool and return to a sample of individuals with comments and amendments. However my understanding of the process of validation is that the questionnaire should be tried in its new form with an appropriate sample from the 2 ethnic minority groups and also that there should be some kind of external validation of the new form of RAQ. Thus the final research question should be, not whether or not individuals think that the questions are acceptable but whether the revised version works as a screening tool.

Secondly, the study seems under resourced and the time-scale very tight. Arranging, interviewing and analysing the interviews from 60 individuals is time-consuming, even if the interviews are short but the translations and discussions about wording which will be essential to this project will make this a longer process. There seems little leeway in terms of time or resources if more interviews than anticipated need to be done or if the project runs over time. I understand the budgeting for the study but it is important that the desire to fit into the CSO category of a small grant does not spoil a good piece of research.

The selection of the sample seems crucial and criteria should be set up by the project team, rather than by a number of practitioners, to make this a non-biased sample.

The role of Dr Hunt is not clear; the research student will need close supervision if she is to carry out high quality interviews and it is important to have on-site support for these and the analysis.

## IMPORTANCE

Project of current relevance in context of social justice/equality issues including the development of culturally sensitive approaches. Project builds on findings from Newcastle Heart project and has potential to deliver a tangible, useable product which accommodates an ethnically diverse population. Findings could have UK wide relevance.

## METHODS

Some concerns:

1. Identification of subjects based on language (spoken/written??) seems appropriate for testing *adequacy of translation* of Rose Angina Q, but may not be for exploring *perceptions* of chest pain across culture. Proposal needs to argue why using linguistic group as proxy for ethnicity.
2. Name search method will lead to difficulties in identifying married women and possibly Chinese subjects.
3. Sample size of 100 from each group sounds ambitious. Why need this? Could quota sampling be more efficient? Need to explain rationale.
4. Need to explain what "select only participants identified by their GP as fit to take part" means. May introduce bias towards certain cases.
5. The screening question is itself part of the issue to be explored by the research. Cultural differences in perception of chest pain will determine responses which could lead to bias in the final sample.
6. Method proposed will pick up only those subjects registered with a GP. How will non GP registered people be involved? What are the implications of omitting them?
7. Lack of recognition of wider contextual factors, e.g. previous dealings with health service regarding chest pain; family/friends experience; geographical effect? They need to expand on how they will take the wider context into account.

## VFM

Good as no overheads and Edinburgh University departmental equipment used. No research staff costs - just project workers costs.

## MODIFICATIONS

1. More thought to method- identification of subjects; method of screening; expansion to more than one geographical location?; non GP cases included?
2. More thought to relevant contextual factors and how to ensure these are captured by the research.

## STRENGTHS AND WEAKNESSES

### Strengths:

- ✓ Current relevance
- ✓ Potential for generalising, wider applicability
- ✓ Tangible output

### Weaknesses:

- ✓ Potential bias in cases resulting from method adopted
- ✓ No acknowledgement and consideration of differences *within* linguistic groups
- ✓ No robust justification of use of linguistic groups as proxy for ethnicity
- ✓ Lack of acknowledgement and consideration of wider context and non-cultural influences

25<sup>th</sup> January 2001

Jennifer Waterton  
Research Manager  
Scottish Executive Health Department  
Chief Scientist Office  
St Andrew's House  
Regent Road  
Edinburgh EH1 3DG

Dear Ms Waterton,

**Re: Small grant application reference CZG/3/2/48: "The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire"**

Thank you for sending us the referees' assessments on the above small grant application. We are grateful for the generally positive and encouraging comments and our responses are attached. This response comes from the applicants and the researcher.

We look forward to hearing from you.

Yours sincerely

Professor Raj Bhopal.....  
Bruce and John Usher Chair of Public Health,  
University of Edinburgh

Dr Sonja Hunt.....  
Honorary fellow,  
Community Health Sciences (General Practice), University of Edinburgh

Ms Lisa Hanna.....  
Doctoral research student  
Public Health Sciences, University of Edinburgh

Enc. (1)



### **Response to Referee 1**

The referee is supportive ("an interesting and potentially useful study") but raises two main concerns, firstly, that "the study does not seem to complete the validation process" (paragraph 2, line 1), and, secondly, that "the final research question should be, not whether or not individuals think that the questions are acceptable but whether the revised version works as a screening tool" (paragraph 2, line 8). As stated in the project summary (Pg 7) and proposal (Appendix 1 Pg 1 "Aims of the proposed project"), this study aims to (1) develop an understanding of the perception, interpretation, significance and expression of chest pain in Punjabi, Cantonese and English speakers, and (2) assess the need for, and feasibility of, modifying the Rose Angina Questionnaire to produce an angina measurement tool valid for use in an ethnically diverse UK population. This study does not aim to complete the validation process but to carry out essential background research into the cultural and linguistic factors affecting interpretation of existing translations. The referee is correct in stating that to ensure cross-cultural validity of a questionnaire, it should be "tried in its new form with an appropriate sample from the two ethnic minority groups" (paragraph 2, line 6). However the proposed study comprises the essential qualitative investigation which must help develop a high quality questionnaire (phase 1) for formal validation (phase 2). We discussed this issue in our research team before submitting the grant, and again on receipt of this comment. We see the research as being best suited to two distinct phases. The small grant application is for phase 1, which is primarily to develop and test field methods. The research questions are designed to be within the scope of a Ph.D. Phase 2 would be suitable for subsequent postdoctoral work.

### **Resources/ timescales**

The referee says "The study seems underresourced and time is tight" (paragraph 3, line 1); "important that the desire to fit into the CSO category of a small grant does not spoil a good piece of research" (paragraph 3, line 6). The outlined timescale and request for resources is based on the experience of the applicants and consideration of the support and resources available in addition to those requested. We have identified the small grant system as suitable and have not squeezed the project in to fit the system. This piece of research is, in our judgement, containable within the timescales we suggested and those of the researchers' Ph.D. project. The highest priority is to establish the methodology.

This study does correspond to the guidelines for small grant work- it is an exploratory study to assess the feasibility of subsequent more detailed work. The guidelines explicitly state that applications for pilot or developmental work are particularly welcomed, that qualitative work is also welcomed, and that the small grant's original purpose was to enable the piloting of ideas that might later form the basis of larger scale projects. We consider that this proposal fulfills all these descriptions and is therefore suitable for small grant funding. In addition it does address the strategic aims outlined by the CSO of tackling inequalities, developing primary and community care, and may contribute to subsequent projects on improving health.

### **Sampling**

The referee says "The selection of the sample seems crucial...make this a non-biased sample" (paragraph 4, line 1). Qualitative research sampling criteria do not aim for statistical generalisability but analytic generalisability,<sup>1</sup> and so a range of people are chosen to represent experience relevant to the research questions. Sampling strategies are therefore more purposive than a truly "non-biased" method such as random sampling; however, qualitative sampling strategies do not undermine the project's credibility as the aim is to generate deep, rich data, from a small number of interviews. Sampling strategies with the quantitative rigour of a positivist approach are less applicable to qualitative work.<sup>2-4</sup> Our team has experience of both quantitative and qualitative methods and our proposal was based on thorough consideration of the potential



sampling methods. We believe we have struck the right compromise. We assure the referee that it is the research team, not a number of practitioners, who will select the sample.

#### Supervision by Dr Hunt

The referee says "The role of Dr Hunt is not clear; the research student will need close supervision if she is to carry out high quality interviews and it is important to have on-site support for these and the analysis" (paragraph 5). Dr Hunt is in extremely close contact with the research student via e-mails at least once or twice a week, has visited Edinburgh to design and advise on the project's development on two separate occasions within the first year, and will play a vital and ongoing role providing constant supervisory support throughout the remainder of the project. The project is being carried out by the research student but with daily collaborative support and advice available from the ethnicity and health team at the University of Edinburgh.

#### Response to Referee 2

The referee foresees the project has the potential to deliver a tangible, useable product, and makes several further suggestions.

#### Language and ethnicity

The referee says "language group [spoken/ preferred] may not be [appropriate] for exploring perceptions of chest pain across cultures...needs to argue why using linguistic group as a proxy for ethnicity" (Methods, point 1)

The project is not using linguistic group as a proxy for ethnicity- the focus is on linguistic rather than ethnic group because language is the most crucial factor in shaping concepts and is not necessarily equivalent to ethnic group; an Indian ethnic group, for example, encompasses several linguistic groups. In order to produce valid results about differences between groups who speak different languages, we need to ensure that different language versions of a questionnaire are conceptually and functionally equivalent. The best way to do this is by the type of in-depth qualitative approach with interviews in the participant's language that we have developed here, as language not only describes our experience but is a formative part of that experience. This project takes this ethnolinguistic approach to understanding people's beliefs about the chest and chest pain in the language with which they experience and express those beliefs. We will take steps towards producing more culturally sensitive survey instruments by ensuring the linguistic and conceptual appropriateness, relevance and acceptability of other language versions of a questionnaire. This study hopes to begin with two key non-English languages and establish the methodology that can be used elsewhere in other ethnic minority languages. We particularly need to develop valid non-English versions of the Rose Questionnaire for the older ethnic minority age groups; hence our choice of people only of age 45 years or over.

#### Name search and marriage

The referee says "name search method...difficulties in identifying married women and possibly Chinese subjects" (Methods, point 2). We emphasise that the identification of Punjabi and Cantonese speakers from a general practice register will, in practice, probably require a combination of methodologies, and that the name search method will be used as an adjunct to practice staff knowledge of their patients. The methodology is flexible and it may be that the practice staff will be the primary identifiers and the name search will be secondary. However, the name search method is effective in identifying people of South Asian and Chinese origin.<sup>5-7</sup> Additionally, our sample is above 45 years of age and it is unlikely that there will be a significant amount of marriage outwith the participants' own ethnic group which would obscure married women's ethnicity (personal communication from Edinburgh's Minority Ethnic Health Inclusion Project's (MEHIP) Linkworker). Where names can be either Chinese or European, for example Lee, they will be included unless the first name is thought to be exclusively European also. So

whilst not a perfect tool, a name search method is nevertheless an effective one. False positives that are included can be usually quickly identified by practice staff, or at the screening stage.

#### Sample size

The referee says "sample size of 100 sounds ambitious..quota sampling" (Methods, point 3). A sample size of 100 is based on unpublished data from the Newcastle Heart Project<sup>8</sup> yielding prevalence rates of positive response to the first Rose Questionnaire question "Have you ever had any pain or discomfort in your chest?" in South Asian and Chinese groups (approximately 11% in Chinese people, 36% in South Asian people). This information gave an approximate minimum estimate of what proportion of people are likely to respond positively to the question. Therefore we estimated an initial identification of 100 people in order to achieve an interview sample of 10 people answering yes to this screening question and ten no. We reiterate, however, that this number is selected only for potential brief telephone contact; recruitment for the interview study (20 participants from each linguistic group) will cease as soon as those numbers are achieved. If the prevalence of positive response is not sufficient to gain an interview sample of ten Chinese people responding yes, we will continue to telephone potential participants until we reach our goal.

#### Role of GPs in excluding participants

The referee requests that we "explain what "select only participants identified by their GP as fit to take part" means", and says that this "may introduce bias" (Methods, point 4). This statement refers to the potential participants' health. Ethical guidelines require General Practitioners to exclude from the study any patient he or she feels are sufficiently physically or psychologically ill that involvement in the project would place too much of a strain on them, cause patient distress or complicate the enquiry. While we will work with general practitioners to minimise bias, they will need to be the ultimate decision makers. It is a requirement of an ethical committee that (1) patients should be healthy enough to participate in a research project (2) that the GP should be an arbiter of that.

#### Screening question- potential bias

The referee says "the screening question is itself part of the issue..cultural differences..will determine responses which could lead to bias in the final sample" (Methods, point 5). As aforementioned, this study is investigative in nature and seeks to explore how a range of people speak about a concept and respond to questions about it in their language. Hence the screening question is chosen not for diagnostic precision but to explore why people respond to the initial Rose Questionnaire question in different ways. We will, of course, have participants with **and** without chest pain at telephone screening, and will be able, at interview, to explore the issue of their initial response.

#### GP registration

The referee asks "the method proposed will pick up only those subjects registered with a GP. How will non-GP registered people be involved? What are the implications of omitting them?" (Methods, point 6). It is extremely uncommon for people in our ethnic groups not to be registered with a GP. 100% of South Asian men and women above 30 years of age<sup>9</sup> and 98% of Chinese men and 99% of Chinese women<sup>10</sup> living in the UK are registered with a general practitioner. Hence, we are confident that the sampling frame for the study does not systematically exclude significant proportions of the ethnic minority communities to be studied.

#### Contextual data

The referee says there is a "lack of recognition of wider contextual factors" (Methods, point 7). The comments are apt. The qualitative methodology proposed for the project will yield rich, contextually relevant information via in-depth semi-structured interviews in which the participant's own narrative can emerge. Qualitative research is particularly sensitive to embedding an

individual's perception and experience within the contexts and constructs that are meaningful to them, and stresses the geographically and temporally localised nature of the results. We are keen not to decontextualise an individual from their social, material and historical environment. These issues may emerge as an individual recounts their experience.

### References

1. Curtis S, Gesler W, Smith G, Washburn S. Approaches to sampling and case selection in qualitative research: examples in the geography of health. *Social Science and Medicine* 2000;**50**:1001-4.
2. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal* 2000;**320**:50-2.
3. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *British Medical Journal* 2000;**320**:114-7.
4. Britten N. Qualitative interviews in medical research. *British Medical Journal* 1995;**311**:251-3.
5. Cummins C, Winter H, Cheng K-K, Maric R, Silcocks P, Varghese C. An assessment of the Nam Pehchan computer program for the identification of names of south Asian ethnic origin. *Journal of Public Health Medicine* 1999;**21**:401-6.
6. Nicholl A, et al. Accuracy of using surnames and forenames in ascribing Asian ethnic identity in English populations. *Journal of Epidemiology and Community Health* 1986;**40**:364-8.
7. Harland J, White M, Bhopal RS, Raybould S, Unwin NC, Alberti KGMM. Identifying Chinese populations in the UK for epidemiological research: experience of a name analysis of the FSHA register. *Public Health* 1997;**111**:331-7.
8. Bhopal R, Unwin N, White M, Yallop J, Walker L, Alberti KGMM et al. Heterogeneity of coronary heart disease risk factors in Indian, Pakistani, Bangladeshi, and European origin populations: cross sectional study. *BMJ* 1999;**319**:215-20.
9. Health Education Authority. Black and Minority Ethnic Groups in England. London: HEA, 1994.
10. Health Education Authority. Health and lifestyles of the Chinese population in England. London: HEA, 1999.



## SCOTTISH EXECUTIVE

---

Health Department  
Chief Scientist Office

St Andrew's House  
Regent Road  
Edinburgh EH1 3DG

Professor R S Bhopal  
Public Health Sciences  
University of Edinburgh  
Medical School  
Teviot Place  
EDINBURGH  
EH8 9AG

Telephone: 0131-244-2248  
Fax: 0131-244 2285  
Robin.bate@scotland.gsi.gov.uk

Our ref: CZG/4/2/25

Date: 14 February 2001

Dear Professor Bhopal

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

Consideration has been given to your application for a small grant and I am pleased to be able to tell you that support is now offered for your project.

Details of the grant conditions are given in the folder/disc "**All you need to know about research grants from the Chief Scientist Office**" published in January 1998, available from your Finance Office and also on our website at [www.show.scot.nhs.uk/cso](http://www.show.scot.nhs.uk/cso). It is important that you continue to consult this document for the duration of the grant. Any potential changes in the substance of the project *must* be discussed with the appropriate research manager.

**The project should start within 6 months of the date of this letter.**

I enclose 2 copies of the **Acceptance of Conditions of Grant** form. One copy is for you to retain, the other copy should, after being signed by yourself, cogramholders and your Finance Officer be returned to me.

JHB00112JULY

## **Appendix 8**

## **Advertisements for bilingual project worker posts**



## **BILINGUAL PROJECT WORKERS NEEDED FOR RESEARCH STUDY (2 posts)**

- Do you enjoy talking and listening to people?
- Are you a fluent speaker in English and Cantonese?
- Are you familiar with Chinese communities in Britain?
- Can you work flexibly with a multi-ethnic research team?

**Location:** Public Health Sciences, University of Edinburgh

**Responsible to:** Professor Raj Bhopal

**Main purpose of job:** To arrange, carry out and assist analysis of interviews about pain and ill-health in Cantonese speaking communities in Edinburgh

### **Duties and responsibilities of post:**

- To work closely with the project researcher, Lisa Hanna, and another Cantonese-speaking project worker
- To assist in arranging interviews by telephone with Chinese community members
- To carry out interviews with community members in Cantonese about pain and ill-health, either in the interviewee's own home or the University
- To assist in the analysis of interviews by discussion with a co-worker in Cantonese, and subsequently with the researcher in English
- To feed back findings to community groups

**Additional information:** The project will last for a minimum of 10 weeks at approximately 12 hours per week @ £12/ hour. Flexibility in hours may be necessary and the project length may be extended. Further details to be discussed.

**Necessary skills:** No qualifications are necessary, although fluency in both English and Cantonese is essential. Experience of interviewing or working in a bilingual capacity with Cantonese speaking communities would be an advantage. Full training will, however, be given, and individuals with good people and language skills with no other experience are encouraged to apply. Shortlisted applicants may be asked to take a short language test to assess bilingual fluency.

For a further information, selection criteria and application details for these posts, please contact **Lisa Hanna, Public Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG. Tel: (0131) 650 3230** (please leave your name and address on the answer machine if outside office hours). E-mail: [Lisa.Hanna@ed.ac.uk](mailto:Lisa.Hanna@ed.ac.uk)

**Completed applications to be submitted by 20<sup>th</sup> June**

## **BILINGUAL PROJECT WORKERS NEEDED FOR RESEARCH STUDY (2 posts)**

- Do you enjoy talking and listening to people?
- Are you a fluent speaker in English and Punjabi?
- Are you familiar with Pakistani communities in Britain?
- Can you work flexibly with a multi-ethnic research team?

**Location:** Public Health Sciences, University of Edinburgh

**Responsible to:** Professor Raj Bhopal

**Main purpose of job:** To arrange, carry out and assist analysis of interviews about pain and ill-health in Pakistani Punjabi-speaking communities in Edinburgh

### **Duties and responsibilities of post:**

- To work closely with the project researcher, Lisa Hanna, and another Punjabi-speaking project worker
- To assist in arranging interviews by telephone with Pakistani community members
- To carry out interviews with community members in Punjabi about pain and ill-health, either in the interviewee's own home or the University
- To assist in the analysis of interviews by discussion with a co-worker in Punjabi, and subsequently with the researcher in English
- To feed back findings to community groups

**Additional information:** The project will last for a minimum of 10 weeks at approximately 12 hours per week @ £12/ hour. Flexibility in hours may be necessary and the project length may be extended. Further details to be discussed.

**Necessary skills:** No qualifications are necessary, although fluency in both English and Punjabi is essential. Experience of interviewing or working in a bilingual capacity with Pakistani Punjabi-speaking communities would be an advantage. Full training will, however, be given, and individuals with good people and language skills with no other experience are encouraged to apply. Shortlisted applicants may be asked to take a short language test to assess bilingual fluency.

For a further information, selection criteria and application details for these posts, please contact **Lisa Hanna, Public Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG. Tel: (0131) 650 3230** (please leave your name and address on the answer machine if outside office hours). E-mail: [Lisa.Hanna@ed.ac.uk](mailto:Lisa.Hanna@ed.ac.uk)

**Completed applications to be submitted by 20<sup>th</sup> June**



**Appendix 9      Language test administered to applicants for  
the post of bilingual project worker**

## Role-play

### Instructions for the assessor.

1. Rewrite the role play first in Cantonese/Punjabi
2. Role-play the script with someone else
3. Tape record the role-play

- A. Now I'd like to ask you a few questions about your health. Do you have any health problems?
- B. *Well, I've been having these headaches...*
- A. And how long have they been bothering you?
- B. *Well, they started about three months ago*
- A. I see. And which part of your head is affected?
- B. *Well, it is right across the front.*
- A. And, can you describe the pain?
- B. *It's a sort of dull and throbbing kind of pain.*
- A. And do they come at any particular time?
- B. *They seem to be, they're usually worse in the morning. I notice them when I wake up.*
- A. I see, and is there anything that makes them better?
- B. *Well if I lie down for a while, they seem to get, they go away.*
- A. Have you had any serious illness in the past?
- B. *I had pain in my chest about seven months ago*
- A. Can you remember when it first came on?
- B. *Yes, well I remember, I got a bad pain in my chest when I was shopping. It was so bad I couldn't breathe.*
- A. And where, in which part of your chest did you feel the pain?
- B. *Right across my chest.*
- A. And what did you do when it happened?
- B. *I had to stop to wait for it to go away.*
- A. And how long did it last?
- B. *About 10 minutes*
- A. So, have you had this, the pain again since then?
- B. No.
- A. Now, as a child did you have any serious illness?
- B. No.
- A. And...
- B. Sorry, I was wrong. In fact I had. I had mumps very badly when I was ten years old.

## Test

### Instructions for the candidate

1. You have interviewed a client in Cantonese/Punjabi. Listen to the taped interview and report back in English the content of the interview. While listening you may complete the table below.

Present problem
How long?
Where exactly is the pain?
Type of pain
How often
Past problem
Where exactly is the pain?
When first noticed?
How long it lasted
Childhood problem
What happened
Type of pain
When

2. Give an oral summary in English of the role-play using the information you have noted down.

## Marking

Candidate's name: _____	Language: _____
Overall results: _____	Date: _____

The task tests the candidate's ability in interpreting from Cantonese/Punjabi into English. Candidates may assume that they have interviewed their client in Cantonese/Punjabi and that they are reporting back orally to the researcher in English.

The candidate should reflect the following skills:

**Completeness:** candidates should demonstrate the ability to transfer from Cantonese/Punjabi to English with the relevant information with no omissions or distortions.

**Accuracy and Appropriateness:** candidates should demonstrate the ability to transmit information, paraphrasing if necessary, thus displaying a sound knowledge of both languages.

**Vocabulary and Syntax:** candidates should use the appropriate choice of words to convey the meaning accurately. Correct grammatical construction should be used, preserving the clarity of the original

**Terminology:** specialist terminology in English should be carefully chosen to interpret the words used in the other language (e.g., sharp/dull/throbbing pain)

### Scoring table

Area	Mark
Completeness	
Accuracy and Appropriateness	
Vocabulary and Syntax	
Terminology	

Each area must be marked out of 7. The candidate must achieve a minimum of 5 out of 7 in each area.

THE CANDIDATE'S INTERPRETING SKILLS SHOULD BE MARKED OUT OF 7 IN EACH AREA.

## **Appendix 10     Training pack for bilingual project workers**

## **TRAINING SESSION 1:**

**Wed 1<sup>st</sup> August**

Please take a few minutes to jot down brief responses to the questions below. Be as specific or as general as you like.

**1a) What is your understanding of what this job is about? What will you have to do?**

**1b) What do you think you will enjoy about this job? What do you think you will find challenging?**

**2a) What are your expectations of these training sessions?**

**2b) What would you like to cover in these training sessions?**

## **PROPOSED RESEARCH PROJECT:**

**The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire.**

### **Introduction**

Coronary heart disease is the commonest cause of death in Britain's white and South Asian populations<sup>1</sup> and the second commonest in the Chinese (unpublished analysis by S Wild & R Bhopal). Within Britain's multicultural society, there are important, unexplained ethnic inequalities in coronary heart disease mortality.<sup>2,3</sup> Scotland's ethnic minority population in 1991 numbered 62, 634 or 1.3% of the total population, mostly (75%) with roots in South East Asia, particularly Pakistan, India and China. The Pakistani community is the dominant group in Scotland and the second largest community is the Chinese.<sup>4</sup> Edinburgh had about 10,000 ethnic minority residents in 1991. There were 1,171 black, 1176 Indian, 2625 Pakistani, 328 Bangladeshi, and 1940 Chinese people in Edinburgh.

Data from England demonstrating concerns about coronary heart disease and associated factors in all ethnic groups almost certainly apply in Scotland. Scotland therefore needs to contribute to research on this ethnicity and health theme. This project will help develop such a programme.

The Rose Angina Questionnaire<sup>5,6</sup> is the most common epidemiological angina screening tool used to assess coronary heart disease prevalence in a population. It is widely applied internationally and in cross-cultural research in Britain. The Newcastle Heart Project shown that this questionnaire performs inconsistently across ethnic groups.<sup>7</sup> There is, therefore, a need for an epidemiological angina screening questionnaire with greater cross-cultural validity.

Most questionnaires are developed in Western English-speaking populations and thus may be culturally biased. Inaccurately translated or modified language versions of such questionnaires in English can yield artefactual results. Often unrepresentative bilingual people have translated the adapted version, without involving monolingual lay people. Qualitative research is essential to good quantitative research in cross-cultural contexts.<sup>8</sup>

### **Results of any pilot studies**

The Newcastle Heart Project (NHP) researchers assessed the performance of the Rose Angina Questionnaire in their sample of South Asian and European participants by analysing the Rose questionnaire outcome and its agreement with a doctor's diagnosis of angina and ECG measurements indicating heart disease.<sup>7</sup> A similar quantitative analysis on the NHP sample of Chinese participants is under way and will inform the proposed study.

### **Aims of the proposed project**

- To develop an understanding of the perception, interpretation, significance and expression of chest pain in three different linguistic groups: Punjabi, Cantonese and English speakers.
- To assess the need for, and feasibility of, modifying the Rose Angina Questionnaire to produce an angina measurement tool valid for use in an ethnically diverse UK population.

### **Research questions**

- Do Punjabi, Cantonese and English speakers differ in the ways they perceive, interpret and express chest pain?
- Are the translations of the Rose Angina Questionnaire in each language, as developed by the Newcastle Heart Project, equally appropriate, valid, acceptable and relevant to lay people from that linguistic group? Also, do they interpret the questions in the same way?

### **Methods, expertise available, statistical power**

Meaning, perception and experience are best investigated, at least initially, by a qualitative approach. Hence, the issue of statistical power does not apply. We will conduct semi-structured



interviews with people above 45 years of age, exploring people's perceptions and expressions of chest pain, and their assessment of the Rose Angina Questionnaire translations. This age group is chosen because the prevalence of both chest pain and angina is likely to be higher in people above 45 years of age and in the Punjabi and Cantonese speaking samples, people above the age of 45 are more likely to prefer to speak their own language. Hence they have the greatest need for accurately translated and adapted versions of the Rose Angina Questionnaire.

#### Sampling and recruitment of study participants

We will recruit General Practices in Edinburgh known to have a high number of the Punjabi and Cantonese speakers. Using a combination of a name search method, known to be effective in identifying Chinese and South Asian ethnic minority populations<sup>9-11</sup>, and the knowledge of practice staff, we will identify from patient registers potential participants from each linguistic group. We aim to obtain a sample of 100 people over 45 years (50 men, 50 women) from each of three linguistic groups (Punjabi, Cantonese and English) for initial telephone contact by a project worker with appropriate language skills. We will select only participants identified by their GP as being fit to take part. The General Practice will send the participant an introductory letter and information pack and request their consent to release their telephone numbers to the researchers. Once express consent forms are returned, practice staff will allow the researchers to telephone the participants. At telephone contact, we will ask some preliminary questions to select a sample of 10 male and 10 female participants from each linguistic group for interview. We will choose ethnic minority participants whose preferred language of response is Punjabi or Cantonese. From each sex and linguistic group, five will have responded "yes" and five "no" to the question "Have you ever had any pain or discomfort in your chest?" Our final interview sample will be 60 participants, 20 from each linguistic group.

#### Data collection

Project workers will have uniform training and will conduct the interviews in the appropriate language, in a location acceptable to participants, preferably their own homes. We will tape record the interviews. The interviews will explore the participants' experience and perception of chest pain. We will ask participants to comment on their interpretation of the items on the Rose Angina Questionnaire to assess their relevance, acceptability and appropriateness to them. We will ask participants to suggest alternatives to the current translations, to suggest possible additional items, and, if bilingual, to comment on the quality of the translation.

#### Data processing and analysis

The objective of the analysis is to investigate how the construct of chest pain is expressed linguistically and conceptually within each ethnic group, and to assess the lay participants' agreement with the previous translation of the Rose Angina Questionnaire. We will collate suggested modifications of the existing versions of the Rose Angina Questionnaire.

The researcher, Lisa Hanna (LH), will analyse the interviews conducted in English. For interviews in other languages, the interviewer and a second bilingual project worker will together extract relevant issues from the tapes and agree on an English equivalent (or its absence). LH and the project worker will then discuss the results. If appropriate, we may use a qualitative software package (such as NUD\*IST), although we have yet to ascertain whether such packages are relevant for this type of material concerning different languages, ethnicity, and health.

Subsequently, we will convene discussions with both groups of professionals and lay representatives of all three ethnic groups, to discuss the relevance, applicability and suggested translation of each item on the Rose Angina Questionnaire cross-culturally, and identify items that (i) are not equivalent across the groups (ii) are specific to each group. The groups will confer and agree on changes, if any, that ought to be made to the existing version of the Rose Angina Questionnaire.

We will feedback for comment any new or amended items that emerge to a selected sample of respondents, and to community groups. We will, therefore, assess face and content validity of the modified versions of the angina questionnaires as part of this adaptation process.

### **Ethical issues**

Ethical approval for this study has been granted from Lothian Research Ethics Committee.

### **Expertise available**

The research team have wide experience in cross-cultural epidemiology. Professor Raj Bhopal is currently developing a multiethnic cardiovascular research programme with Dr Sushmita Wiebe as research associate. Dr Sonja Hunt is an experienced social epidemiologist and qualitative researcher with wide expertise in working with cross-cultural questionnaires. The doctoral researcher, Lisa Hanna (LH), is a Ph.D. student works closely with all of those above. Contacts and colleagues include the Newcastle Heart Project research team and the research team at the University of Newcastle currently working on a CRC funded qualitative project exploring smoking in South Asians. Within Edinburgh, we have links to the Scottish Ethnic Minorities Research Unit and the Minority Ethnic Health Inclusion Project. We are also working on a Scottish Office-funded project on the use of tobacco and alcohol questionnaires in ethnic minorities.

### **Timetable**

We aim to complete the selection of participants, interviews, analysis and feedback to participants and to community groups and health experts by the end of October 2001.

### **Research outcomes**

This project will contribute to the development of a cross-culturally valid measure of angina for use in future multi-ethnic epidemiological surveys. It will also lead to an increased awareness of how chest pain is perceived and expressed in three ethnic groups. Such information may help to achieve greater responsiveness to a range of ethnic experience in the health services.

Outcomes of this research will be of relevance to current NHS and Scottish Executive initiatives. It will provide valuable information on the conduct of participative research with ethnic minorities, and increase knowledge concerning the challenge of cross-cultural comparability in survey research. The study will contribute to assessing health needs of ethnic minorities and the delivery of ethnically appropriate health care and the detection of coronary heart disease both in primary care and on a population survey basis.

### **Dissemination**

The information arising from this study will form part of the researcher's doctoral thesis. We will circulate results to the Chief Scientist Office, to community groups and to general practices in Edinburgh.

### **Key references**

1. Wild S.,McKeigue P. Cross sectional analysis of mortality by country of birth in England and Wales, 1970-1992. *British Medical Journal* 1997;**314**:710.
2. Balarajan R. Ethnicity and variations in mortality from coronary heart disease. *Health Trends* 1996;**28**:45-51.
3. Bhopal R, Unwin N, White M, Yallop J, Walker L, Alberti KGMM *et al.* Heterogeneity of coronary heart disease risk factors in Indian, Pakistani, Bangladeshi, and European origin

- populations: cross sectional study. *BMJ* 1999;**319**:215-20.
4. Dalton, M. and Hampton, K. Scotland's ethnic minority community 1991. A census summary. Scottish Ethnic Minorities Research Unit Fact Sheet Number I. 1994.
  5. Rose G. The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organisation* 1962;**27**:645-58.
  6. Rose GA, Blackburn H, Gillum RF, Prineas RJ. Cardiovascular survey methods. Geneva: WHO, 1982.
  7. Fischbacher, C. M., Bhopal, R., White, M., Unwin, N., and Alberti, K. G. M. M. The comparative performance of the Rose angina questionnaire in South Asian populations. *Journal of Epidemiology and Community Health* 54(10), 786. 2000.
  8. Hunt S. Cross-cultural issues in the use of quality of life measures in randomized controlled trials. In Stagnat M, Hays R, Fayers P, eds. *Quality of Life Assessment in Clinical Trials*, Oxford University Press, 1998.
  9. Harland J. Identifying a representative sample of UK Chinese for epidemiological research. *UK Society for Social Medicine* 509.
  10. Coldman AJ, Braun T, Gallagher RP. The classification of ethnic status using name information. *J.Epidemiol.Comm.Health.* 1988;**42**:390-5.
  11. Nicholl A, et al. Accuracy of using surnames and forenames in ascribing Asian ethnic identity in English populations. *Journal of Epidemiology and Community Health* 1986;**40** :364-8.

# **CROSS-CULTURAL COMPARABILITY IN SURVEY RESEARCH- SUMMARY OF PRINCIPLES AND PROBLEMS**

**Author: Lisa Hanna, Public Health Sciences, University of Edinburgh**

## **Introduction and background**

Cross-cultural research has many conceptual and methodological challenges. These issues have been topics of study and debate for many years, particularly in domains such as cross-cultural psychology, psychiatry, and quality of life. However there is a lack of a standard way to achieve cross-cultural comparability across different disciplines. Particularly in biomedicine, there is still a need for an increase in the cultural appropriateness of existing questionnaires.

Health is a socially defined construct and cannot therefore be viewed as independent from the form of society in which it is studied. Given that most health status measurement instruments are developed and validated in Europe or the USA, great care should be taken to ensure that such tests are not culturally specific to the West. Hunt (1998) has summarised basic principles of cross-cultural research. "[When] taking a questionnaire and adapting it for use in several languages and cultures in order to compare or aggregate data across cultures...it is an absolute requirement that both the items on the questionnaire and the responses to them are conceptually and functionally equivalent in every language and culture concerned...and that the underlying concept is present in and salient to the populations of all participating countries".

Uncritically applying standard "Western" questionnaires in studies of minority populations can give false results. Cultural differences in understanding, interpreting and responding to questions are responsible for many of the systematic differences that have been observed in cross-cultural surveys. It is therefore important to ensure that the content of questionnaires is not culturally biased. Bias results from failure to distinguish between universal concepts accepted across multiple cultural groups, and concepts which have meaning only within a specific cultural group or socioeconomic context. Therefore in terms of comparing cultures rather than investigating single cultures, it is crucial to develop and evaluate health questions that are universally meaningful. It should not be assumed that a simple translation of an English questionnaire will make it meaningful and valid in other groups. A simple "back" translation can be misleading as it does not show to what extent words and phrases are conveying the same underlying meanings and associations. It is important to be aware of basic sociolinguistics and the fact that "vocabulary is not merely a string of words; immanent within it are societal textures" (Deutscher 1973). Therefore, translation of questionnaires should not be a simple ritualistic technique but an arduous and creative process involving, at the very least, committee discussion. Within large-scale epidemiological research, a procedure of forward and back translation followed by committee review, (as used in, for example, the Newcastle Heart Project) is still widely considered "state of the art".



Additionally, although only bilingual people are often used in translation techniques, they can be socioeconomically, educationally and linguistically unrepresentative of the ethnic group to be sampled, and often translate into the high form of the language as opposed to the colloquial or idiomatic form. Therefore the views of monolingual lay representatives should be incorporated in the review process as much as possible.

However, cultural sensitivity and equivalence of wording of questionnaire items are not the only basic requirements of an accurate and culturally valid second language version of a questionnaire. It has been noted that "diligence in translation may not by itself be a key factor in achieving instrument reliability" (Hendricson 1989). In addition to translating items, it is vital to consider the issue of comparability of response formats. For example, even a simple yes or no response can contain different cultural connotations. Response scales (e.g. never, sometimes, often, very often) are often not equivalent in many cultures. The researcher also needs to be aware of the conventions governing response behaviour in different cultures. Varying degrees of deferential attitudes to health care professions may provide distorted responses; courtesy bias and the direction of bias can also vary between cultures. In addition, there is evidence that people will give an answer to a culturally irrelevant or incomprehensible question in order not to reveal their lack of understanding. This indicates that sound cultural investigation and awareness is required.

Researchers can not assume that there is multicultural equivalence or ease of translation of terms perceived to be functional or technical. The more common a disease or health marker, often the more difficult it is to translate given the accumulation of cultural meaning arising from its common usage. Even physiological and anatomical descriptive terms can vary substantially in their nuances and connotations across languages and groups and so it should not be assumed that a measure is acceptable, appropriate or relevant in every culture.

#### Some key references (others available on request)

Hunt S. Cross-cultural issues in the use of quality of life measures in randomized controlled trials. In Stagnet M, Hays R, Fayers P, eds. *Quality of Life Assessment in Clinical Trials*, Oxford University Press, 1998.

Deutscher I. Asking questions cross-culturally; some problems of linguistic comparability. In Warwick D, Osherson S, eds. *Comparative Research Methods*, pp 163-88. New Jersey: Prentice Hall, 1973.

Hendricson WD et al. An approach to developing a valid Spanish language translation of a health status questionnaire. *Medical Care* 1989;27:959-67.

# **The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

**Ms Lisa Hanna**

**Public Health Sciences, University of Edinburgh**

**Supervisors: Professor Raj Bhopal & Dr Sonja Hunt**

## **Presentation Overview**

- Introduction and background to the project
- Findings from literature review
- Proposed research plan
- Conclusion
- Discussion

## Ethnicity

- The social group a person belongs to as a result of a mix of cultural factors including language, diet, religion, and ancestry

“Research on the health of migrants and ethnic minorities has helped to advance our understanding of disease aetiology and can also be helpful for the communities concerned.”

Chaturvedi & McKeigue, 1994.



## **Introduction**

- The UK's multicultural society has unexplained ethnic inequalities in coronary heart disease (CHD) mortality (Balarajan 1996, Bhopal et al 1999)
- The Rose Angina Questionnaire is commonly used to assess CHD prevalence
- The Newcastle Heart Project has shown that this questionnaire performs inconsistently across ethnic groups in Britain
- There is, therefore, a need for an epidemiological angina questionnaire with greater cross-cultural validity- this case study aims to develop the process to do this

“Concepts of health and illness may differ between cultures and communication difficulties may occur when assessing someone of another culture, particularly if compounded by language barriers.”

Kai & Hedges, 1999.

## RAQ

“...successful use of questionnaires is known to require standardisation of wording and interview technique.....exact standardisation is essential.”

Rose, McCartney & Reid, 1977

“Chest pain may be experienced, understood, interpreted and described differently in different cultures.”

– Fischbacher et al., unpublished work.

## **Case study proposal**

### **Aims**

- To develop an understanding, using qualitative methods, of the perception, interpretation, significance and expression of chest pain in three different linguistic groups: Punjabi, Cantonese and English speakers
- To assess the need for, and feasibility of, modifying the Rose Angina Questionnaire to produce an angina measurement tool valid for use in an ethnically diverse UK population

### **Research Questions:**

- Do Punjabi, Cantonese and English speakers differ in the ways they perceive, interpret and express chest pain?
- Are the translations of the Rose Angina Questionnaire as developed by the Newcastle Heart Project, equally appropriate, acceptable and relevant to lay people from that linguistic group?
- Can we take steps towards developing versions of the Rose Angina Questionnaire that are more valid for use in cross-cultural surveys?

## **Objectives of this presentation**

- To summarise a literature review on the conceptual and methodological challenges of screening for angina in multi-ethnic studies
- To describe proposed methods to improve the cross-cultural comparability of this screening process

## **Methods**

- Literature review using a research literature collection, Medline 1966-2000, BIDS 1951-2000 and citations from references. Search terms included "cross-cultural AND questionnaire", "cross-cultural AND adaptation" and "Rose Angina Questionnaire OR WHO chest pain questionnaire OR angina OR chest pain AND cross-cultural OR ethnic OR minority groups"
- In-depth interviews with Punjabi, Cantonese and English speaking communities in Edinburgh will investigate the perception and expression of chest pain and the acceptability of the Rose Angina Questionnaire in different linguistic groups

### **Literature finding 1: Cross-cultural survey research: principles and problems**

- Questionnaires developed in Western English-speaking populations may be culturally biased when used in other ethnic groups
- Inaccurate translations and non-equivalent questionnaires can yield artefactual results (eg Deutscher 1977, Salber 1980, Warnecke 1997, Hunt 1993, 1998)
- Non-salience of items/ omission of culture-specific items/ response choices and norms vary
- Translations were often by unrepresentative bilingual researchers- no involvement of monolingual lay people
- Qualitative research with the lay population is essential to good quantitative research in cross-cultural contexts (Hunt 1998)
- The table below summarises the principles of cross-cultural modification relevant to the Rose Angina Questionnaire (after Bullinger et al 1993).

**Minimal:**

Forward/ backward translation in each language  
Clear cut description of translation and evaluation process

**Optimal:**

Qualitative research in lay populations  
More refined, reiterative translation process using more translators and focus groups  
Testing performance (clinical/ criterion validity) of questionnaire in population sample

## **Literature finding 2: Cross-cultural use of the Rose Angina Questionnaire**

- Geoffery Rose, who developed the questionnaire, wrote that
  - ⇒ "the questionnaire has been translated into various languages" (but made no further comment on the process)
  - ⇒ "methods may need to be adapted to the local culture and language"
- "Differences in prevalence of questionnaires positive for ...[angina]...have to be viewed in the light of cultural differences between national groups that might affect the perception of the standard questions"
- The RAQ has been used in several non-English speaking countries-some examples summarised in the table below (references available on request)
- The translation, adaptation and validation procedure for using the Rose Angina Questionnaire in different languages and cultures was seldom described, and never in the recommended depth.
- Procedures for cross-cultural adaptation of questionnaires, developed in social epidemiology, have not been applied in cardiovascular epidemiology as far as we are aware

## **Case study proposal**

### **Design and methods**

- Select 10 men and 10 women over 45 years of age from each of 3 linguistic groups- Punjabi, Cantonese and English
  - Ethnic minority participants who prefer to respond in Punjabi or Cantonese
  - Equal numbers who have responded "yes" and "no" to the question "Have you ever had any pain or discomfort in your chest?"
- Semi-structured interviews explore participants' experience and perception of chest pain
- Participants comment on their interpretation of Rose Angina Questionnaire items to assess their relevance, acceptability and appropriateness
- Participants suggest alternatives to current translations and possible additional items
- Professionals and lay representatives from all three ethnic groups convene to discuss changes to questionnaire

## Conclusions

The translation of the Rose Angina Questionnaire into other languages has been inadequate for valid cross-cultural research. A more rigorous approach is required.

This project will

- contribute to the development of a cross-culturally valid measure of angina for use in multi-ethnic epidemiological surveys
- lead to an increased awareness of how chest pain is perceived and expressed in three ethnic groups
- help to achieve greater responsiveness to a range of ethnic experience in the health services

## *What is epidemiology?*

EPIDEMIOLOGY is the study of the  
DISTRIBUTION and DETERMINANTS  
of DISEASE in human POPULATIONS

## **WHAT IS QUALITATIVE RESEARCH?**

The goal of qualitative research is to understand why people feel or behave in the way that they do: to understand experiences and concerns. The methods used enable us to explore views, experiences, behaviour and attitudes in depth and detail.

- Qualitative research is aimed at answering questions such as:  
What?  
How?  
Why?
- Qualitative research explores concepts in natural settings (e.g. the community, home) rather than experiments. In this study we will be carrying out interviews (semi-structured to allow comparison of views and experiences on similar range of issues)
- Qualitative research emphasises meanings, experiences, depth, detail and views of all participants.

## **SAMPLING**

### **What is a sample?**

In research a sample refers to a selection of people who are chosen to represent a particular group or population

### **Qualitative sampling methods**

Qualitative samples do not aim to be representative

Sample sizes are small (usually between 30-80) so that topics can be explored in depth and detail

There are two main methods:

- **FORMAL SAMPLING**- based on existing databases or existing list of people (e.g. GP register)
- **PURPOSIVE SAMPLING**-to illustrate a feature or process the researchers are interested in
  - Snowball sampling
  - Typical case sampling
  - Extreme case sampling
- **NB: often one research project may use all forms of sampling as one method may be unsuccessful**



## Sampling in qualitative research

- Relevance
- Potential to generate rich information
- Analytic generalisability
- Potential to generate believable explanations
- Ethics
- Feasibility

Miles & Huberman, 1984(In Curtis, 2000)

### TYPES OF INTERVIEWS

- Structured interviews
- Semi-structured interviews
- Unstructured interviews

## INTERVIEW SKILLS

### Open questions

"How do you feel about.....?"

"What do you think about.....?"

"Could you tell me about.....?"

### Probes

"Why.....?"

"Could you tell me more about....."

"What did you think about that....."

### Closed questions

"Did you enjoy that?"

"Was that the only time it has happened?"

### Checks

".....is that right?"

"So you think.....?"

## ETHICS

When you are interviewing someone remember they always have the following **RIGHTS**:

- To know why you are doing the research
- To be able to stop the interview whenever they want to
- To remain anonymous if they want to
- To see what information you are recording
- To change anything that you are writing down or go back to any previous questions or information or alter or add to it
- To have their views and information kept confidential
- To express any opinions about your questions or your research
- To refuse to answer any questions and to only give the information they think is important

### **CONFIDENTIALITY**

Confidentiality protects the identity of research participants. Researchers have a legal responsibility (Data Protection Act) to research participants to protect their identity.

#### **Oath of confidentiality**

I, the undersigned, have understood the necessity for non-disclosure of any personal information I am exposed to throughout the course of the above study, and confirm that I will treat this information with total confidence both whilst involved with the project and after its completion.

Name:

Signature:

Date:

### **INFORMED CONSENT**

- Researchers must ensure that participants have enough information about the study to be able to make an informed choice about whether they want to take part
- Researchers must ensure that the participant understands this information and is making a voluntary, informed decision about whether or not to take part

### **INTERVIEWING SKILLS - CODE OF CONDUCT**

- Always introduce yourself and show your ID
- Always introduce the research
- Make sure you listen carefully to the answers
- Don't use leading questions
- Don't be judgemental
- Only ask one question at a time
- Try not to talk over people or hurry them up without being sensitive
- Use simple language
- Avoid interpreting people's answers
- Always thank people for taking part
- Ask if you can ring again if you have anything you wish to clarify
- Ask if the participant would like you to send them a summary of the research outcomes

### **THE SEQUENCE OF QUESTIONS**

- |                                  |                                                                                      |
|----------------------------------|--------------------------------------------------------------------------------------|
| <b>1. Introduction</b>           | Introduce yourself, explain the purpose of the interview                             |
| <b>2. 'Warm up'</b>              | Easy, non-threatening questions                                                      |
| <b>3. Main body of interview</b> | Covers the main purpose of research. Logical progression. Risky questions asked last |
| <b>4. 'Cool-off'</b>             | Straightforward questions to diffuse tensions                                        |
| <b>5. Closure</b>                | Thank you and goodbye                                                                |

### **QUESTIONS TO AVOID**

- **Long questions:** Participant may only remember part of the question
- **Double-barrelled questions:** Break down into several questions
- **Proverbs/ sayings:** Allow the participant to think in their own words
- **Double negatives:** Confusing- "do you agree or disagree that stress is not harmful to your health?"
- **Jargon and technical terms:** Keep it simple- don't use words the participants will not understand
- **Leading or biased questions:** "Why do you like exercise?" assumes that they do
- **Ambiguity:** "Do you often get questionnaires?" - Who does the "you" refer to? What do you mean by "get" questionnaires?

## A guide to the qualitative interview schedule

### Key points

- The aim of qualitative research is to see the world from others' perspective and to investigate their beliefs and behaviours.
- In order to gather good quality data, it is important that rapport and trust are established between interviewer and participant.
- Please try to react sensitively to each participant and avoid a formal professional divide between you- we are keen to access people's private opinions and views.
- The interview should try to be as much like a normal conversation as possible, ideally, however, the participant does most of the talking.
- Your challenge as an interviewer is to steer the subject matter towards the core topics and retain a clear focus, whilst also being sensitive to the participant's story and responding to them as individuals.
- You are not expected to ask every question in the order it appears on the interview topic guide- instead, you must try to create and facilitate a discussion that covers all the topic guide areas in as natural a way as possible. Be responsive, creative and flexible in order to cover the topic guide. **HOWEVER**, questions in bold on the topic guide relate to the core research aims and questions that we covered in Training Session 1 and we **must** get this information to satisfy the research proposal.
- Whilst attempting to cover the topic areas, however, try not to openly ignore anything the participant says, or talk over them unless absolutely necessary. Instead, acknowledge what they've said is interesting and gently steer them towards the topic guide. For example, you could say "That's interesting...I was also particularly interested in something you said a while ago that I'd like to pick up on...you mentioned you had terrible pain once- could you tell me a bit more about that?"
- Also bear in mind that if someone seems unresponsive, sometimes keeping silent as an interviewer is a good thing and will give the participant space to say more. Don't feel you have to respond instantly to every answer. Nodding or murmuring that you have understood will often allow the participant to speak further.
- However sometimes you may have to use verbal prompts and probes to elicit more information.

### Areas to cover

This interview covers two broad lines of enquiry. The first is a fully qualitative enquiry when you are aiming to gain insight into pain and ill-health from the point of view of the people you are interviewing. The telephone screening interview sheet should be taken into the interview and used as a prompt to facilitate discussion.

The second part relates to the need to involve lay and monolingual people in the assessment of the quality of a translated questionnaire. We will ask participants to assess the relevance, acceptability and appropriateness of the translations of the Rose Angina Questionnaire that we have, and to suggest alternative and better ways of asking the questions. As mentioned on the topic guide, only do this **AFTER** you have covered the previous topics about general health and illness, experience of pain, discuss of chest pain etc. We want people to discuss pain and chest pain in their own words before seeing the translated questionnaire and responding to it- you can feed back phrases they might have used in the first part of the discussion and ask if that word would be more appropriate to use in the questionnaire.

## Qualitative Analysis

### *What is the aim of qualitative analysis?*

Qualitative analysis is looking for themes in human experience; we want to identify recurring statements or behaviours and label, describe and summarise them. We are interested in the participant's view of the world and allow their own voice to be heard.

### *Key components of qualitative analysis:*

- Overlap of data collection and analysis
- Less structured, more flexible
- Participatory, interactive, dynamic
- Allows lay (versus professional) meanings and descriptions to redefine the problem under study

### *Analysing our interview data: a preliminary summary*

Analysing qualitative data is time-consuming, labour-intensive, and requires project workers to interpret and think deeply about the data. Hence we are estimating that analysing a one-hour interview will take up to five hours.

You and your co-worker will listen to the interview tape with Lisa and provide a translation and commentary in English. We will need to develop this process together as this type of research has rarely been carried out previously. Most often the researcher is given an English translation of the interview and analyses it in English. In this study we are interested in what people say in their own language, and so you as project workers will need to play a more active role in the analysis, using your cultural insight and opinions, rather than acting simply as a translator. You will also use your cultural insight to identify themes in what the participants are telling you about the way in which they perceive and express their world. These themes can provide insight into the cultural beliefs and we will compare the themes emerging from each of the three groups- English speakers, Cantonese speakers and Punjabi speakers.

As mentioned, Lisa will develop the analysis further as we go along.

**FIRSTLY:** we must try to answer the core research questions as covered in Session 1:

- Do Punjabi, Cantonese and English speakers differ in the ways they perceive, interpret and express chest pain?
- Are the translations of the Rose Angina Questionnaire in each language, as developed by the Newcastle Heart Project, equally appropriate, valid, acceptable and relevant to lay people from that linguistic group? Also, do they interpret the questions in the same way?

For each core question from the topic guide, you will write down the participant's response to it and any key phrases or differences in understanding words.

**SECONDLY:**

We will try to analyse participant's general beliefs by summarising their statements about pain, general health, and any other issues covered in the topic guide. We will be interested in what people say, how they say it, and what cultural/ social knowledge they draw on and if this differs across ethnic groups.



# **Practicalities of the post**

## ***Contacting participants and arranging interviews***

Participants have been initially recruited by their GP and sent a contact pack concerning the study. If they are happy to be telephoned, participants have returned a consent form to their GP giving their permission to be contacted by us. Project workers will be given the consent forms that participants have returned to their GP. These consent forms will state the participant's name and telephone number. These consent forms therefore contain personal information and as such are protected by the Data Protection Act. It is crucial that you allow no-one else to see these consent forms and ensure that you do not lose, misplace or leave them unattended. After having used the consent forms, they must be returned to the University as soon as possible where they must be kept in a locked filing cabinet. You must code each consent form with an identifying number and in all other instances and documents refer to the participant only by this number, not their name. Project workers will telephone the participant and conduct a brief *telephone screening interview*, which will last no more than a few minutes.

Interviewers should keep a note of each time they contact or attempt to contact a participant (using their identifying number).

On the sheets provided, write the participant's ID number and time of telephone interview, and record their responses to the questions. Based on their answers to this telephone interview, project workers will need to arrange a mutually convenient time and place for interview. Participants should be asked where they would like to meet; we encourage participants to be interviewed in their own home, but if this is difficult for them we will pay their travel expenses to come to the University. If a participant does wish to be interviewed at the University, you must contact Lisa and let her know the time of the interview and she will arrange a room. We suggest you arrange to meet the participant at the entrance to the Medical School and escort them upstairs to the department. Please ask the participant to fill in a travel expenses form (to be supplied on request), attach receipts, and post back to Hazel King.

## ***Interview basics***

Before beginning the interview, introduce yourself by name and post and thank the participant for agreeing to meet with you. All project workers will be issued with ID cards. These should be shown to the participant when meeting them for the first time. These ID cards should also be shown to the Medical School security staff in the Warder's Office if you need to meet with the team in Public Health Sciences

outside office hours. We urge you to keep these ID cards safe as they cannot be replaced and must be returned to the University at the end of the study.

Remember to be confident, calm and unrushed and try to establish a friendly, relaxed rapport with participants prior to interview. Some small talk can help. Try not to appear overly professional or distant; we are keen to make participants feel comfortable and able to talk openly and informally. Give a brief summary of why you are interviewing the participant and read through the interview consent form with them before giving them two copies to sign. Give one copy to the participant and return the other to Lisa as soon as possible. Inform the participant that you are going to begin taping the interview and get their permission to do so. Place the tape recorder as close to both you and the participant as possible. The most important part of the initial stage of the interview is to give a brief summary of what the study is about and **stress confidentiality**. Participants should be repeatedly assured that what they say is confidential and will not be passed on to their doctors or other community members and that all interview tapes will be fully anonymised so the only person who will know what they themselves have said is the interviewer, who has signed an oath of confidentiality. Please make sure you don't talk to anybody about the interview and maintain the anonymity of participants. Carry out the interview (see separate notes).

### ***Tape recorders, audio cassettes and batteries***

Interviewers will be supplied with tape recorders, 90 minute cassettes and batteries. On some tape recorders it is important to ensure that the VOR (voice activated recording) switch is in the off position, otherwise the beginning of each statement is lost. If the interview lasts more than 45 minutes (i.e. one side of the tape) it is not necessary to change the tape to the other side- the recorder will do so automatically. Project workers should always carry spare batteries and cassettes. Renew the batteries after every 2-3 interviews. **Remember to press record at the beginning of the interview!**

Immediately after each interview, project workers should check and label each tape with the following information: Participant ID number, date of interview, approximate duration of interview, project worker name. **Completed consent forms and tapes must be kept in a secure place before being brought into Public Health Sciences the next time you are here for an analysis session.**

After each interview, project workers should make short field notes. These notes should record anything interesting said by the participant after the tape recorder has been switched off. Also jot down any comments or thoughts you have about how the interview went, your feelings about the interview, how you felt the participant

responded etc. In addition, please note down any questions you feel you missed out (it is not always possible to remember to cover everything!).

### ***Payment and expenses***

Your travel expenses to and from the interview will be covered in the payment you receive for your interview. The initial interview should take 45 minutes to 1 hour. Instead of the rate of £12 per hour that you will receive for the analysis, you will be paid £17 for the interview. This is to cover the cost of the telephone screening interview, your travel expenses to and from the interview, and any extra time spent writing notes after the interview. Subsequent analysis will be paid at the rate of £12 per hour. It is likely that we will pay you per completed interview and analysis, and ad hoc payment forms can be submitted to Lisa before the 1<sup>st</sup> of each month to be paid on the 28<sup>th</sup> of each month.

### ***Health and safety issues***

See attached departmental guidance.

# Safety of Staff visiting the public in their own homes

## Guidance for PHS, Medical School, University of Edinburgh

Guidance for staff within PHS who are involved in interviewing the public in their own homes, taking blood samples, or similar. For ease I have referred to them as "the interviewer".

### Equipment for Interviewer

1. Mobile phone
2. Personal alarm
3. Photographic ID
4. First aid kit for car
5. Car breakdown notice etc

Remember to take all these things with you, and keep your phone charged and switched on!

### Administration procedures

Risk assessment of work to be done BEFORE work starts.

1. Keep office diary of staff appointments - keep it up to date - with details of patient being visited, address etc.
2. Interviewer login/out with office at least at the beginning and end of the day, if not before and after each appointment (e.g. using CRISYS). Even if not using CRISYS draw-up cascade of contacts.
3. Report and keep a log of any incidents or problem patients
4. Prepare a routine of action to be taken if interviewer needs assistance or fails to make contact.

When a project first starts or when a new member of staff starts, a risk assessment should be made of the interviewing etc to be done. This involves thinking about the hazards involved and what steps can be taken to minimise the risk to staff and patient. As well as using these guidelines to reduce the risks of working in other peoples homes, there must be an assessment of any extra hazards involved, such as manual handling, or taking blood samples. Hazardous biological or chemical substances require a COSHH (Control of Substances Hazardous to Health) assessment. Forms and guidance available from H&S web page or H&S adviser.

Some important measures are:

- Keeping an up-to-date appointments diary in the office, so that the last location of the interviewer, or their appointments for that day can be found quickly if they fail to make contact or require assistance.
- It is therefore important that the interviewer keeps in touch with the office, either by phoning in to someone there or by using an automated system such as "CRISYS". Whether using CRISYS or not, draw-up cascade of contacts, e.g.
  1. Almost always call Jane in the office
  2. If she is not available or on leave call Andrew in office
  3. ....

These people should know what the emergency routine is, and have access to necessary numbers/appointments diary etc. e.g. copy of sheet at end of guidelines.

Make sure you do make contact, or you might set off the emergency routine, when you are not in trouble, or worse, people will assume you forgot to phone when you are actually in trouble.

- Decide upon a course of action for emergency situations and make sure all office staff are aware of it e.g.

Interviewer has failed to make contact at the end of the day:

1. Call interviewer's mobile
2. Call interviewer's home number
3. Call last appointment, check they arrived and left...

...Call Police with interviewer's details, car registration number etc.

Ideally staff should visit in pairs, but where this is not possible due to concern about intimidating the patient or staff availability, it is important they plan visits carefully:

- It is useful to keep a log of any incidents or problems with patients, so that the interviewer can refer to these before visiting them.
- The interviewer should think about the location of the visit, how busy is it, will it be dark etc.
- How are they getting there, do they have their phone, alarm etc
- Remember to keep the office informed of any changes of plan.

Once in the patients home, care should be taken not to intimidate or provoke them, it is their home, remember you are a visitor:

- Say who you are, why you are there and show your ID, the local police promote this as a measure against bogus callers.
- Check who you are speaking to, do not enter the house at all if the appropriate person is not available
- Wait to be invited in or ask if it is ok to come in, let them lead the way.
- Listen to your instincts, you may decide not to enter e.g. if the person is drunk or aggressive.
- Check as you go in how the front door locks
- Take only what you need into the house, and do not spread your belongings around. It is then easier to collect them if you need to leave in a hurry.
- Don't get trapped, check for the exits and try to sit nearest the door.
- Try not to react to bad, smelly or dirty surroundings.
- You can ask for dogs or other animals to be put in another room.
- Remain alert; watch for changes in mood etc. If you feel at risk leave as soon as possible.
- If you are prevented from leaving or threatened, stay calm and try to control the situation.



## Essential Information for:

Project Name:	
Interviewer's name:	
Interviewer's Mobile number:	
Interviewer's Home Number:	
Appointments diary with:	
Interviewer's Car Registration:	
Interviewer's Car Description:	
Cascade of login/logout contacts	
Name	Number
Emergency Routine	
Trigger for initiating routine:	
Contact	Number

## **Task Checklist**

- Code each consent form with a participant ID number. Telephone the people who have returned their consent forms to their GP. Keep a note of unsuccessful attempts to telephone each participant.
- Carry out the telephone screening interview. Record the responses on the appropriate form. Set up a face-to-face interview with
  1. five participants who answer
    - a) that their preferred language of response is Punjabi (and are of Pakistani origin) or Cantonese
    - b) "yes" to the question "Have you ever had any pain or discomfort in your chest?"
  2. five participants who answer
    - a) that their preferred language of response is Punjabi (and are of Pakistani origin) or Cantonese
    - b) "no" to the question "Have you ever had any pain or discomfort in your chest?"The participants will also be interviewed according to their approximate age group (in order to access a range of age groups) and we will interview equal numbers of men and women.
- Remember to ask the participant for their address if you are interviewing them in their own home and record this separately on the pre-interview details form. Keep this form highly secure.
- Contact the office to let us know when and where you are carrying out the interview
- Check your tape recorder has working batteries and carry spare batteries and tapes.
- Travel to the participant's home (or the University if you have arranged an interview in the department). Show your ID card.
- Before interviewing, give the participant two copies of the interview consent form to sign (either in English or their own language). Give one copy to the participant and keep one copy yourself.
- Carry out the interview using the topic guide. Tape each interview. Make sure the tape recorder is close to both the participant and yourself. The sound quality will not be adequate otherwise.
- Immediately after the interview, check each tape, label it and fill out the field notes form.
- Contact the office to let us know you have safely completed the interview
- Bring the pre-interview details form, the General Practice consent form, the telephone screening interview form, the interview consent form, the interview tape and the field notes form to your next analysis session so that they can be securely stored in the University.



**Field work checklist**

<b>Tape recorder</b>		
<b>10 x 90minute tapes</b>		
<b>10 AA batteries</b>		
<b>ID card</b>		
<b>Telephone screening interview forms (&amp; doctors' names)</b>		
<b>Interview consent forms</b>		
<b>Field notes forms</b>		

**Appendix 11      Oath of confidentiality for bilingual project workers**



Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone 0131 650 1000  
or direct dial 0131 650  
Fax 0131 650 6909  
Website <http://www.ed.ac.uk>

#### DATA PROTECTION ASSURANCE:

#### **The challenge of cross-cultural comparability in survey research: a case study of the Rose Angina Questionnaire**

##### Oath of confidentiality

I, the undersigned, have understood the necessity for non-disclosure of any personal information I am exposed to throughout the course of the above study, and confirm that I will treat this information with total confidence both whilst involved with the project and after its completion.

Name:

Signature:

Date:

**Appendix 12      Pre-interview details form**

## **PRE-INTERVIEW DETAILS**

<b>Participant ID:</b>	<b>Project worker:</b>
<b>Date telephoned:</b>	<b>Date/ time to be interviewed:</b>
<b>Address of interview:</b>	<b>Any further information (directions)</b>

**Appendix 13      Interview consent forms in Urdu, Chinese  
and English**



Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

انٹرویو کے لئے اجازت نامہ

ریفرنس: آپ کی تکلیف اور بیماری کے بارے میں سمجھ

میں نے ساتھ دیا ہوا معلوماتی ورقہ پڑھا ہے اور سمجھا ہے۔ میں اس مطالعہ میں حصہ لینے پر رضامند ہوں اور انٹرویو لینے والے کے ساتھ درد اور بیماری کو سمجھنے کے بارے میں بات کرنے کے لئے تیار ہوں۔ میں متفق ہوں کہ اس انٹرویو کو ریکارڈ کر لیا جائے۔

میں جانتا/جانتی ہوں کہ میں اس انٹرویو سے کسی وقت بھی نکل سکتا/سکتی ہوں۔ اور جس سوال کا جواب نہیں دینا چاہتا/دینا چاہتی نہیں دوں گا/گی۔ میں یہ بھی جانتا/جانتی ہوں کہ جو معلومات میں دے رہا/رہی ہوں وہ مکمل رازداری سے رکھی جائیں گی اس مطالعہ میں حصہ لینے سے میری دیکھ بھال اور ڈاکٹری علاج پر اثر انداز نہیں ہوگا۔

_____	_____	_____
تاریخ	دستخط	حصہ لینے والے کا نام
_____	_____	_____
تاریخ	دستخط	اجازت لینے والے کا نام
_____	_____	_____
تاریخ	دستخط	تفتیش کار کا نام





Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

## 接受訪問同意表

### 關於：對病痛及生病的理解

本人已閱讀資訊冊並理解其中的內容。本人同意參加這項研究活動，樂意會見訪問員並與他/她談論我對病痛及生病的理解。本人同意採用磁帶錄音的方式記錄談話內容。

本人明白，我可以隨時退出此項研究活動，亦不必回答我不想回答的問題。本人亦明確，我所提供的資訊將會嚴格予以保密，參加此項活動不會影響我的醫生為我提供的任何醫療服務。

_____ 參與者姓名	_____ 簽署	_____ 日期
_____ 同意表接受者姓名	_____ 簽署	_____ 日期
_____ 研究者姓名	_____ 簽署	_____ 日期



Community Health Sciences (Public Health Sciences Section)  
SCHOOL of CLINICAL SCIENCES and COMMUNITY HEALTH

The University of Edinburgh  
Medical School  
Teviot Place  
Edinburgh EH8 9AG

Telephone 0131 650 1000  
or direct dial 0131 650

Fax 0131 650 6909

Website <http://www.ed.ac.uk>

### INTERVIEW CONSENT FORM

#### **Re: Your understanding of pain and ill-health**

I have read and understood the information sheet. I agree to participate in this study and am happy to meet with an interviewer to discuss my understanding of pain and ill-health. I agree that this interview can be taped.

I understand that I can withdraw from the study at any time and that I don't have to answer any questions I'd rather not. I also know that the information I give is strictly confidential and that the care I receive from my doctor will not be affected by taking part in the study.

_____	_____	_____
Name of participant	Signature	Date

_____	_____	_____
Name of person taking consent	Signature	Date

_____	_____	_____
Name of researcher	Signature	Date

**Appendix 14      Interview field notes form**

<b>Project worker:</b>	<b>Date of interview:</b>
<b>Duration of interview:</b>	<b>Place of interview:</b> home/ university
<b>Participant ID:</b>	<b>Participant language:</b>
<b>Participant age:</b>	<b>Pain/ discomfort in chest?</b> Yes      No

Field notes

Please use the space below to make any notes you feel necessary concerning the interview. Please give your impression of the participant, for example how open they were, how you feel the interview went, or any interruptions. Please also note anything down that the participant said of interest that was not recorded on tape. Please also take a few minutes to review the interview in your mind and note down any questions you think you have missed out.

**Appendix 15      Form for recording translated data from non-English interviews**

### Descriptive analysis

*List of topics for translation and analysis. Whilst listening to the interview tape, data was recorded on the form following this list.*

#### **CORE ANALYSIS**

- Experience/ views on pain & discomfort in chest, if any
- What participant interpreted the question "Have you ever had any pain or discomfort in your chest?" to be about
- Did the participant think there was a difference between a pain and a discomfort?  
Meanings/ examples of what these words mean?  
Any other information?
- Where is "chest"?  
Any other information?
- Assessment of RAQ1a: "Have you ever had any pain or discomfort in your chest?"
  - Understandable?
  - Different or better way of saying it?
  - What do they understand by pain?
  - What do they understand by discomfort?
  - What do they understand by chest?
  - Any other information?
- Assessment of RAQ 1b: "Have you ever had any pressure or heaviness in your chest?"
  - Understandable?
  - Different/better way of saying it?
  - What do they understand by "pressure"?
  - What do they understand by "heaviness"?
  - Any other information?
- Assessment of RAQ1c: "Do you get it when you walk uphill or hurry?"
  - Understandable?
  - Better or different way of saying it?
  - Do they understand what the "it" refers to?
  - What do they understand by "uphill"?
  - What do they understand by "hurry?"
- Assessment of RAQ 1d: "Do you get it when you walk at an ordinary pace on the level?"
  - Understandable?
  - Better/ different way of saying it?
  - What do they understand by "ordinary pace"?
  - What do they understand by "on the level?"
  - Any other information?

- **Assessment of RAQ1e: "What do you do when you get it while you are walking?" "Stop or slow down" "Carry on"**
  - Understandable?
  - Better/different way of saying it?
  - Do they understand what "it" refers to?
  - What do they understand by the phrases for "stop or slow down" and "carry on"?
  - Any other information?
- **Assessment of RAQ1f: "If you stand still, what happens to it?" "Relieved" "Not relieved"**
  - Understandable?
  - Better/different way of saying it?
  - What do they understand by phrase for "stand still"?
  - Do they understand what "it" refers to?
  - What do they understand by words for "relieved" "not relieved"
  - Any other information?
- **Assessment of RAQ1g: "How soon " " 10 minutes or less"" more than 10 minutes"**
  - Understandable?
  - Better/different way of saying it?
  - Do they understand what the "how soon" refers to?
  - What do they understand by each phrase?
  - Any other information?
- **Assessment of RAQ 1h: "Will you show me where it was?"**
  - Understandable?
  - Better/different way of saying it?
  - interpretation?
  - Any other information?
- **Assessment of RAQ 1i "Do you feel it anywhere else?"**
  - Understandable?
  - Better/ different way of saying it?
  - Do they understand what the "it" refers to?
  - Any other information?
- **Assessment of RAQ 1j "Did you see a doctor because of this pain?" "What did he say it was?"**
  - Understandable?
  - Better/different way of saying it?
  - What do they understand by "doctor"?
  - Which pain is the question referring to?
  - Any other information?
- **Assessment of RQ 2a: "Have you ever had a severe pain across the front of your chest lasting for half an hour or more?"**
  - Understandable?
  - Better/ different way of saying it?
  - What do they understand by "severe pain"?
  - What do they understand by "front of chest"



**Any other information?**

- **What do they think they are being asked about when asked "Have you ever had a severe pain across the front of your chest lasting for half an hour or more?"**
- **Assessment of RQ2b: "Did you see a doctor because of this pain?"**
  - Understandable?
  - Better/ different way of saying it?
  - Interpretation?
  - what do they understand by "see a doctor" "doctor" "pain"?
- **What do they understand by the term "angina"?**

**Any other information?**
- **Knowledge about symptoms of angina- description? Where did they get this knowledge?**

#### **EXTRA ANALYSIS**

- **General health**
- **Experience of pain and descriptions**
- **Concerns about health**
- **Attitudes to doctors/ consultation behaviour**
- **Attitudes to medication**
- **Cause of heart disease/ knowledge about heart disease**
- **Influences on health/ causes of health and disease**
- **Source of information about health**
- **Experience/ attitudes to questionnaires**
- **Why did they agree to be involved? How were they recruited?**

#### **OTHER ANALYSIS**

- **Any other topic emerging**

**Descriptive analysis**

<b>Participant ID:</b>	<b>Date/time interview</b>
<b>Interviewer:</b>	<b>Participant age:</b>
<b>Participant language:</b>	<b>Date analysis</b>

**CORE/ EXTRA/ OTHER ANALYSIS (circle relevant description)**

<b>Question/ topic</b>	<b>Tape no.</b>	<b>Comments/quotes</b>
<i>Question written in here</i>		<i>Translated quotes from the participant written in here, in addition to further comments from the project workers and specific words or phrases written in the participant's own language. Where the participant used an English word or phrase, this was noted.</i>

**Appendix 16      Timeline for key stages of project  
preparation and field work**

### **Application for further funding (£9,000) to Chief Scientist Office**

20 <sup>th</sup> October 2000	Application submitted
15 <sup>th</sup> December 2000	Referees' comments received
25 <sup>th</sup> January 2001	Referees' comments responded to
14 <sup>th</sup> February 2001	Funding confirmed
1 <sup>st</sup> May 2001	Funding start date
End of June 2002	Final report submitted

### **Ethical approval**

16 <sup>th</sup> August 2000	Application for ethical approval submitted
1 <sup>st</sup> September 2000	Application considered at sub-committee meeting
7 <sup>th</sup> September 2000	Management approval granted from primary care trust subject to ethical approval
20 <sup>th</sup> September 2000	Sub-committee returned comments
27 <sup>th</sup> October 2000	Comments responded to
13 <sup>th</sup> November 2000	Sub-committee returned further comments; comments responded to, agreeing to comply
December 2000	Ethical approval granted
April 2001	Following discussion with supervisors and piloting, participant documents amended slightly for clarity and ease of translation
19 <sup>th</sup> April 2001	Amended documents submitted to ethics committee
15 <sup>th</sup> May 2001	Ethical approval granted to use amended documents
22 <sup>nd</sup> May 2001	Amended document submitted for primary care trust approval
17 <sup>th</sup> August 2001	Following failure of GP sampling strategy, LH spoke to the ethics committee chairperson to discuss alternatives; chairperson insisted on written application
27 <sup>th</sup> August 2001	Submitted request to ethical committee for approval to a) contact participants from GP register without patient's active consent; b) community-based sampling
7 <sup>th</sup> September 2001	Ethical committee meeting

1 <sup>st</sup> October 2001	Ethical committee granted approval for community based sampling strategy or for 'practice's regular interpreter' to call patients
------------------------------	-----------------------------------------------------------------------------------------------------------------------------------

### **Meetings with relevant community organisations and gatekeepers**

3 <sup>rd</sup> April 2001-23 <sup>rd</sup> May	Discussion with key community group leaders and relevant organisations to gain advice and support for the project
-------------------------------------------------	-------------------------------------------------------------------------------------------------------------------

24 <sup>th</sup> May- early June	Discussion with a number of other relevant organisations about bilingual project worker recruitment; circulation of advertisements
----------------------------------	------------------------------------------------------------------------------------------------------------------------------------

### **General practice-based sampling**

Nov 2000-Aug 2001	Liason with three general practices; identification of English, Pakistani and Chinese participants; screening of lists of potential participants by doctors; posting of contact packs (to all identified Pakistani and Chinese and half of the English-speaking sample); collection of returned consent forms
-------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

November 2001	Posting of contact packs to the second half of the English-speaking sample; collection of returned consent forms
---------------	------------------------------------------------------------------------------------------------------------------

### **Bilingual project workers**

Early June 2001	Advertisements circulated
20 <sup>th</sup> June 2001	Received applications for posts
28 <sup>th</sup> June 2001	Shortlisted applicants contacted for interview
2 <sup>nd</sup> July 2001	Shortlisted applicants interviewed (RSB, SW, LH) and language tested
1 <sup>st</sup> - 8 <sup>th</sup> August 2001	Training sessions

**Research interviews**

4 <sup>th</sup> July- 19 <sup>th</sup> July 2001	English telephone screening and interviews
22 <sup>nd</sup> Nov- 6 <sup>th</sup> Dec 2001	English telephone screening and interviews
8 <sup>th</sup> August-24 <sup>th</sup> Nov 2001	Cantonese telephone screening, interviews and translation/ discussion sessions
8 <sup>th</sup> Aug 2001- 29 <sup>th</sup> Jan 2002	Punjabi telephone screening, interviews and translation/ discussion sessions